

**The Lived Experience of
Compassionate Love
At End of Life**

**Submitted by
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degree of Doctor of Philosophy (Social Work)**

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Declaration of Originality

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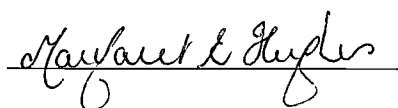
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Margaret Hughes

7th August 2009

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Abstract

This thesis is an investigation of how people experience the death and final arrangements of a significant other person who died at home from a life limiting illness. Inspired by my own lived experience, and recognizing that subjectivity would influence this research, I decided to employ the qualitative approach of heuristic enquiry to discover new meanings from a time marked by irreplaceable loss and critical decision making.

Previous studies have shown that in contemporary western society, an expected death predominantly occurs in a hospital, hospice or aged care facility. Consequently, an expected death at home is unusual and outside common experience. Furthermore, Australian social policy is committed to relocating death back into the community, not just as a cost saving measure but also based on the ideology of a good death. I argue that to make death at home a realistic option for more people, greater awareness of how people experience the death and final arrangements is needed. I also claim that despite death being an ubiquitous lifetime event, limited opportunities arise to discuss matters relating to a dead person. Given that the traditional theories of grief and bereavement have promoted 'letting go' and detaching from a relationship with the deceased, the discourse surrounding what occurs in the site of the home when an expected death prevails from a history of disease, remains largely sequestered from people's conversations. Consequently, the aims of this research have been to discover a rich understanding of the experience at home from those with lived experience for the purpose of informing and extending the support by people at end of life.

The findings from this research were generated from the wisdom and insights of twenty eight Tasmanian people. By applying the six stages of heuristic enquiry to discover new meaning from human experience, three temporal dimensions emerged, casting light upon a range of human experience. A deep and committed examination of this topic using self reflexivity and thematic analysis, discovered that the spirit guiding people's decision making at end of life is a set of experiences and responses that I have chosen to call compassionate love.

In the final stage of this enquiry known as the creative synthesis, I propose a model which demonstrates how five interdependent practices of compassionate love enable the expression of human qualities of care. These practices facilitate a rich array of people's strengths, resources and capacities providing benefits not only for the person receiving the care but unveiling the potential for self growth and transformation in the journey at end of life. These findings have relevance to social work intervention at end of life and beyond because it is possible that these qualities of care may be obscured in the chaos generated by grief and overlooked when attention is directed towards the negative outcomes that so often represent the experience of bereavement.

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Chapter 1: Introduction to the Thesis

You will find as you look back upon your life that the moments when you have truly lived, are the moments when you have done things in the spirit of love (Henry Drummond, cited in M.I.L.K. 2002, p. 146).

Introduction to the Chapter

This introductory chapter to my thesis provides an overview of how people attend to the death and final arrangements of a significant other person who died at home from a life limiting illness. In this chapter I claim that it is compassionate love which guides peoples' decision making at death and beyond, facilitating the expression of a diverse range of human capacities, resources and strengths. In this chapter I also present the qualitative research approach of heuristic enquiry, describing how it is applied, and why it is an appropriate research method for investigating people's lived experience. I bring this chapter to a close by presenting the structure and content of my research plan.

A Death at Home

A death at home from a life limiting illness is an unfulfilled goal for most people in contemporary western culture. Few opportunities arise for discussing the experience of being at home in the company of someone close as death prevails from a history of disease, and the subsequent days leading up to the time when matters of body disposal and memorialisation are arranged. The topic of caring for a dead person is dialogue seldom broached because such conversations can be awkward to speak, uncomfortable to hear, thereby leaving the experience forever unspoken. Along with a declining transfer of knowledge passed onto successive generations and the reluctance to discuss personal matters relating to death, the public discourse around what happens when someone close dies at home is disappearing. I claim that because people working in end of life often

withdraw assistance following the death, this research can offer rich information to extend the support provided by services that enable a person to die at home.

This thesis presents the findings from the collective wisdom generated by 28 Tasmanians who attended the death and final arrangements of a significant other person who died at home from a life limiting illness. Borne from a deep and personal interest to know how this time of crisis is experienced by other people in the community, this research illuminated four key discoveries.

The first discovery concerns people's experiences and responses throughout this time. This is a time marked by irreplaceable loss, deep grief and critical decision making, when exhaustion, uncertainty, incessant demands and the behaviour of other stakeholders all play a crucial part in shaping a person's experience. People describe their experience as difficult and hard, while simultaneously being rewarding and a privilege.

The second discovery reveals that care does not cease at the time of death. Living people demonstrate an ongoing relationship with dead people, shown in their actions and attitudes involving such activities as washing and dressing their deceased person; placing treasured items in their coffins; honouring people's wishes for a preferred option of cremation or burial; celebrating their life through a personalised service and forever maintaining bonds with the deceased person. Care for a deceased person beyond final arrangements is evident in people incorporating their deceased person in conversations; placing their photos around their house and considering their influence when making important decisions.

The third discovery involves the power of compassionate love which guides decision making throughout the death and final arrangements. I claim that compassionate love is demonstrated in the attitudes and actions of people throughout five practices: responsibility; commitment; concern; respect; and knowing. My research adapts Frohm's (1957/1984, p. 28) theory of love using it as a platform to represent the lived experience of compassionate love at end of life. I have devised a model which conceptualises compassionate love as a gift because it enables people to contribute to the life of another as they approach end of life and attend to matters of death. I maintain that

not only does compassionate love allow people to do extraordinary things for another person, but it also provides benefits for those who provide the care. By participating in this difficult and hard time, people's strengths emerge to raise awareness of their own potential. The capacities, strengths and resources of people illuminated throughout this study include courage, hope, determination, humour, acceptance and empathy. The discovery of these qualities is significant because they risk remaining sequestered for two reasons. First, by the chaos created by grief which can seem all-enveloping and second, by medicine's prevailing focus upon potential problem behaviours and increased morbidities throughout bereavement.

The final discovery to emerge from this thesis concerns the need for appropriate professional support. For the people involved in this study, their journey has brought self-discovery and growth, and I maintain that people providing support must not interrupt this process by inadvertently disrupting the flow of compassionate love. I believe this can be avoided by workers paying respect to the lived experience of compassionate love at end of life offered by this thesis.

This research evolved from my own lived experience with death and bereavement, instilling within me a deep curiosity to discover meaning within human experience. Recognising that subjectivity would influence this research, I decided to illuminate new meaning by the application of the research method known as heuristic enquiry. The following section of this chapter sheds light upon this distinctive research approach.

An Heuristic Approach

This thesis applies a framework of heuristic enquiry which is:

a way of engaging in scientific research through methods and processes aimed at discovery; a way of self-inquiry and dialogue with others aimed at finding the underlying meanings of important human experiences (Moustakas 1990, p. 15).

An heuristic approach always requires the researcher's subjectivity to be an essential feature of the research method (West 2001, p. 128). This research approach uses

reflexivity to discover and explicate new knowledge, promoting self-awareness by employing the researcher's voice throughout the research process. The starting point is always the researcher's ability to claim inside membership with the people being studied and a 'passionate yet disciplined commitment' (Douglass & Moustakas, 1985, p. 40) to the research question is borne from a personal desire to find answers to a research question of subjective significance. As Moustakas (1990) explains:

Heuristic enquiry is a process that begins with a question or problem which the researcher seeks to illuminate or answer. The question is one that has been a personal challenge and puzzlement in the search to understand one's self and the world in which one lives. The heuristic process is autobiographical, yet with virtually every question that matters, there is also a social and perhaps universal significance (Moustakas 1990, p. 15).

The merits of applying an heuristic approach to social research are threefold. First, given that the entry point to heuristic enquiry must be a personal quest to discover meaning from lived experience, the reason is clearly identified for why a particular field of social research is being investigated. Second, heuristic enquiry provides an immediate connection with those being studied, thereby providing a legitimate reason for asking questions of such a personal nature. Finally, heuristic enquiry intentionally positions the investigator at the centre of the research process, providing transparency, exposing biases, and giving value to subjectivity. While critics may believe that the nature of heuristic enquiry is narcissistic and self-indulgent, the 'social and perhaps universal significance' (Moustakas 1990, p. 15) of this particular enquiry justifies its application.

This thesis is presented in accordance with the six stages of heuristic enquiry created by Moustakas (1990). These stages are known as initial engagement, immersion, incubation, illumination, explication and creative synthesis. The first stage of heuristic enquiry known as initial engagement requires a process of self-dialogue and inner searching (Moustakas 1990, p. 28). Self-dialogue leads to the focus of the enquiry and eventually to the specific research question. Throughout the initial engagement, the terms in the research question are defined and clarified. The research processes operating

at this time include: a deep curiosity with an autobiographical connection; observations; reflections; readings; discussions; and journal writing.

The second stage of heuristic enquiry known as immersion, follows the formulation of the research question and involves such processes as: reviewing the existing literature on topics relevant to the research question; a thorough exploration of the methodology informing the research process; the recruitment of participants; and the collection of data. Immersing oneself in the process will bring new understandings and greater knowledge of the phenomenon being explored.

The third stage of heuristic enquiry known as incubation, 'allows tacit, intuitive and often unconscious processing of the research to continue' (West 2001, p. 129). Having accumulated a mass of data, it is during this stage that the researcher purposely disengages from the study and new insights to the phenomenon may arise at unexpected moments.

The fourth stage known as illumination, sees new insights gradually emerge, whereby the data is examined and analysed for meanings. 'Illumination as such, is a breakthrough into conscious awareness of qualities and a clustering of qualities into themes' (Moustakas 1990, p. 49). Closely aligned to illumination is the fifth stage of heuristic enquiry, explication, whereby deeper meanings are revealed from the themes, qualities and components that have been discovered from the previous research stage.

The sixth and final stage of heuristic enquiry is known as the creative synthesis which 'invites a recognition of the tacit-intuitive awareness of the researcher, knowledge that has been incubating over months through processes of immersion, illumination and explication of the phenomenon investigated' (Moustakas, 1990, p. 52). In the creative synthesis, the knowledge accumulated throughout the study is expressed as a 'poem, story, drawing, painting or by some other creative form' (Moustakas, 1990, p. 32).

In the following section of this chapter, an outline of the structure and content is provided for the purpose of further orienting the reader to the heuristic approach applied in this study.

The Research Plan

The structure and content of this thesis is according to the following plan. Each stage of this enquiry is introduced with a definition, along with a brief overview of the distinguishing features of the particular stage.

The first stage of heuristic enquiry known as initial engagement, is documented in chapter 2, identifying the motives as to why I chose this specific focus of enquiry. This chapter makes apparent the research question and defines the terms of reference.

The second stage of this research focuses on the immersion stage and comprises chapters 3 and 4. In chapter 3, a review of the research literature is presented in relation to where people die in economically advantaged countries and how people attend to the moment of death and final arrangements. This chapter also examines the retrospective and current research on grief and bereavement. Chapter 4 highlights the research methodology, drawing attention to the philosophical assumptions underpinning the study. I also present the research methods and procedures used in this study to collect and analyse the data.

The third stage of heuristic enquiry, referred to as incubation, is detailed in chapter 5. In this chapter, the challenges presented from researching death and bereavement are described and reasons are given for consciously disengaging from the enquiry.

The fourth stage, illumination, is documented in chapters 6, 7, 8 and 9. Chapter 6 introduces the participants and the people who died, along with the research strategy used to report the findings. Chapters 7, 8 and 9 present the findings from the research derived from the contributions of participants in their interviews and personal correspondence, augmented with my journal entries.

The fifth stage, explication, is presented in chapter 10 whereby 'a more complete apprehension of the key ingredients is discovered. Additional angles, textures and features are articulated' (Moustakas 1990, p. 31). In chapter 10, the findings of the study are discussed in relation to where they converge and diverge from the research literature.

The sixth and final stage of heuristic enquiry known as the creative synthesis, is presented in chapter 11. In this chapter, I present a model of the lived experience of compassionate love at end of life which is my conceptualisation of the research, describing how people attend to the death and final arrangements of a significant other person who died at home from a life limiting illness. I also discuss the implications of these findings and propose a number of recommendations for social work practice. The thesis concludes with a letter which conveys my gratitude to the people who offered their experiences for this study, highlighting the power of engaging with the research method known as heuristic enquiry.

Concluding Comments to the Chapter

This introductory chapter has shed light upon the influences shaping my research approach to studying the experiences of people who were constant companions to a significant other person who died at home from a life limiting illness. The character of heuristic enquiry resides in the fact that the methodology employed for the purpose of illuminating new meanings will influence each step in the entire research endeavour.

Stage 1: Initial Engagement

The task of the initial engagement is to discover an intense interest, a passionate concern that calls out to the researcher, one that holds important social meanings and personal, compelling implications. The initial engagement invites self-dialogue, an inner search to discover the topic and question. During this process one encounters the self, one's autobiography and significant relationships within a social context (Moustakas 1990, p. 27).

Stage 1 of this enquiry, details the critical incidents in my life which inspired me to research people's experiences of caring for a significant other person who died at home from a life limiting illness. As the pages unfurl, I describe the context in which this study is located, and provide the reasons for undertaking this research. I explain how this topic has relevance to social work practice along with its contribution to my own social work practice in palliative care. I also present the research question and define the terms of reference which guide this enquiry.

Chapter 2: A Specific Focus of Enquiry

Introduction to the Chapter

Moustakas (1990, p. 13) explains that in the heuristic process, ‘the initial data is within me’. I believe that the disclosure of this ‘initial data’ serves a dual purpose. First, the underlying motivation to study a specific focus of enquiry is made transparent and the position taken by the researcher is exposed for public scrutiny. Second, by identifying one’s own encounter with the phenomenon being studied, the researcher is supplied with a genuine reason to connect with people who have had a similar experience. This experience offers a legitimate reason to ask people questions of an intimate nature for the final purpose of:

reaching into deeper and deeper regions of a human problem or experience and coming to know and understand its underlying dynamics and constituents more and more fully (Moustakas 1990, p. 13).

In the following section of this chapter I present my story of how I attended to the death and final arrangements of a significant other person who died at home from a life limiting illness.

My Relationship with Death and Dying

The inspiration to explore people’s experiences of mortality was borne from my own relationship with death and dying. When I was twenty four years of age, I moved interstate to study at university. Several days after enrolling, I received a phone call from my father to tell me that my mother had been diagnosed with cancer. I remember the news coming from my father like a shock wave, and hearing the worry in his voice, I was unable to think of any words which could adequately express what I felt. I asked to speak to my mother who calmly explained that she was hopeful that the six-week course of radiotherapy planned to start in the following week would reduce the size of the

tumour. She asked me not to worry and told me that everything would be alright. I listened with a heavy heart, realising that the certainty of life which I had grown accustomed to had suddenly become very tenuous. I don't recall consciously or otherwise making the decision to return to my parents, but the following day I booked my ticket home, abandoning my plans to study interstate. This was indeed a journey none of us had chosen, but one which would eventually transform all of us. Most of all, this journey taught me that in life, death matters.

My mother lived her dying for fourteen months and not wanting to die, expended every breath of life before she succumbed to death. Sensing her end of life, my father, my brother and I maintained a bedside vigil for several days. She was no longer able to eat or drink, spending much of her time asleep with her eyes open, which I always found extremely distressing. I remember sitting beside her, watching her breathing and thinking that every breath would be her last. When she did eventually die, I remember I laughed because I was so relieved, but I chose not to share this experience with anyone until some time later because I thought my response was so inappropriate.

My mother died at home on 1 May 1989 at 4.40pm, in the company of my father, my brother and myself. I remember that she moved her head to look at my brother's face in the moments before she died and I wished that instead it had been my face that she had looked at. It was through the wisdom gained over the years, that I later understood the significance of connecting with her first-born child.

My father and I dressed my mother in a nightdress I had chosen and I held her close and told her how proud I was of her and that I would always miss her. My father phoned the doctor, who had been very kind and supportive throughout my mother's illness. He arrived soon afterwards, offering his condolences and attended to the necessary paperwork. We waited for the funeral directors to arrive. They were solemn and respectful and gently lifted her tiny body into a long plastic bag while we all stood by, watching them carry her down the front steps into their vehicle. They drove off and I felt relieved. I also felt very worried for my father.

In the haze of the days that followed, my father, my brother and I finished organising the funeral that my mother had begun planning prior to her death. We also met with family and friends, accepting their sympathy and sharing their sorrow. On the day of the funeral, I recall being in the kitchen looking out the window and seeing my father standing alone, in the garden, staring at the ground. Despite living under the same roof, we found it impossible to utter any words of sorrow to one another to describe the depth of despair we felt.

I remember we drove to the chapel before the funeral service to see my mother again for the very last time. Kissing her small, gaunt face and touching her hands, I remember being surprised how different her skin felt to the softness I was familiar with, and could only liken it to the feel of cold, smooth, wax. I was also surprised to see how death had released all of her life, leaving nothing behind but her physical shell. I remembered how she worried that she would be cremated alive and so my visit was to honour my promise that it would never happen, and to see her body again before it was transformed to ashes. The funeral service seemed brief and when it had finished, we drove to the crematorium. Seeing her casket move behind the curtain at the close of the ceremony was almost unbearable for it was then that thoughts flooded my mind of never being able to touch her again. We returned to my father's house and offered hospitality to family and friends, seeking their comfort and sharing their memories. I remember looking across the room filled with people and seeing the deep grief on the face of my mother's twin sister as she spoke with family and friends.

Some weeks later, I was contacted by a bereavement worker and asked whether I would like to meet with her. Along with the doctor and palliative care nurses, she had been a great support to my parents in the months leading up to my mother's death. Being curious, and thinking that I needed some exit point from this relationship, I agreed to meet with her in a small café. During our conversation, I recall her telling me that she had never seen anyone in death as angry as my mother had appeared, and from that very moment onwards and for many years later, I felt a deep sense of failure. The meaning I made from her remark was that we had somehow failed to provide comfort to my mother in the final months of her life, although I now believe that she did not intend to convey this message. It was almost a decade later whilst reading the lines from Dylan Thomas's

poetry, 'Do not go gentle into that good night ... Rage, rage against the dying of the light,' that I realised my mother did not want to die and she did not want to leave the people she loved. I suddenly understood that her death was done in a way which honoured a life that she so desperately did not want to leave. If anger was the emotion she chose to express then it was an apt way to depart from the life she so greatly valued.

In the years following my mother's death I became interested in working in the funeral industry. I enrolled in a social work degree at university believing that this would be an appropriate pathway to working in the field of death and dying. Eventually I found myself leaning towards a career in palliative care and upon graduating, began work in a community palliative care service providing bereavement support to people whose lives had also been shattered by the loss of someone close. While listening to people telling their stories of loss, I became interested in finding out how people experienced the time of death and beyond. People described their caring throughout their significant other person's dying and at the time of death, but often needed prompting to speak about what transpired from the moment of death onwards. When encouraged to continue, people recalled how they attended to the deceased person's body; how they started making plans for the funeral and how they coped during a time of overwhelming grief. Some people described the disparity between how they thought the time of death and the funeral arrangements would transpire, and how in reality those events unfolded. Reflecting upon these stories, and remembering how I thought my mother's death would bring an end to the caring, made me wonder how other people in the private space of the home experienced the time of death and final arrangements. The decision to restrict the experience of participants to the site of the home was never intended to position death at home as a 'gold standard' for everyone. My rationale was based on my assumption that people could regulate to some extent the event of death, thereby offering insight to what people did in the presence of death in the privacy of their own home. I began to read the literature on death and dying and realised that the management of death in western society reflected contemporary ways of living. I realised that there was a strong relationship between death and late modernity.

My practice wisdom as a social worker employed in a palliative care service made me realise that the majority of registered clients in that service were not dying at home.

Reading the research literature on place of death made me aware that the majority of people in economically advantaged countries eventually die in a public setting rather than in the site of their home. Data collected from the Tasmanian Palliative Care Service for the period 2002—2003 revealed that only 31 percent of registered clients died at home, while the remainder died either in a hospital, hospice or nursing home (Eager et al. 2004, p. 64). I also recognised that many people would transfer to an acute care setting in the final days before their death. I assumed the reason why people died in an institution was due to people in contemporary society being uncomfortable with the event of death, wanting those with professional expertise to direct the way. I also gathered that people were not encountering death at a personal level as frequently as they did in previous generations. I realised that there was a declining transfer of knowledge passed onto succeeding generations and consequently the information and anecdotes around what to do with someone who died at home was no longer common currency. Furthermore, I recognised that in my workplace I was an active participant in discussions which referred to people's deaths in terms of *good* or *bad*, judged according to whether the dying person's personal goals had been achieved. People's autonomy, self-determination and choice rated as moral imperatives in workers' assessments of what was either a good or a bad death. I recognised too how palliative care workers had a duty of care to identify bereavement risks which could potentially complicate a person's grief journey. I knew that some clients who needed ongoing bereavement support may be assessed as complex or dysfunctional.

My Reasons for Undertaking the Research

My efforts to locate an interpretive study from the perspectives of people who witnessed the death in their own home and were subsequently involved in making final arrangements for their deceased person yielded few results. I believed that the knowledge which could come to light from such a study could add to the body of knowledge which attends to death and final arrangements for the purpose of promoting people's well-being in the community. I was sure that social work could enhance ways of supporting people in the community dealing with end of life issues and bereavement. Social work is a profession which identifies well-being as a key concept in people's lives

and is committed to furthering knowledge of how best to help people to achieve their potential. The International Federation of Social Workers defines social work as the profession which:

promotes social change, problem-solving in human relationships, and the empowerment and liberation of people to enhance wellbeing. Utilizing theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments (International Federation of Social Workers 2000).

Well-being is identified in the Australian Association of Social Work's Code of Ethics (2002, p. 5) declaring it as a core aim and commitment of the profession.

The social work profession is committed to the pursuit and maintenance of human well being. Social work aims to maximize the development of human potential and the fulfilment of human needs through an equal commitment to working with and enabling people to achieve the best levels of personal and social well being (AASW 2002, p. 5).

The pursuit of well-being is not the sole province of social work (Payne 2007, p. 72). Many human services generally value people's well-being, but social work by the very nature of the name is concerned with the social aspects of people's lives, thereby providing an important and unique contribution to people dealing with issues of end of life and bereavement. This view is supported by George who states:

social work, a profession which sits outside the curative medical arena, demonstrates a different relationship with death and enables consideration of social and preventative aspects in health service work (George 2000, p. 269).

The Australian Government's policy objective for palliative care is to attend to people who are dying in more cost effective ways, which means a concerted effort to move people away from public institutions back out into the community. A report commissioned by the Tasmanian Government (Eager et al. 2004, p. i) identified that Tasmania offered only 50 percent of recommended designated palliative care beds, acknowledging a 22.4 percent increase in the demand for palliative care services between 2000 and 2003, with only 52 percent of estimated need being provided. It is evident that

to make community care a reality, people need to be supported not only throughout the dying trajectory, but at the event of death and throughout bereavement. I believe that social work operating at the interface of people's environments, providing what Bern-Klug, Gessert and Forbes (2001) describe as appropriate, competent and context specific support, can play a key role in helping people to explore their options for death and beyond. For these reasons, I believe sensitive research which investigates people's experiences of death and early bereavement can be justified.

Arriving at the Research Question

Thinking deeply about my own lived experience, augmented by my practice wisdom and initial readings from the research literature on end of life, helped to guide me towards a specific focus of enquiry. The process of arriving at the research question evolved over a number of months, nurtured through discussions with many people and in consultation with my research supervisors. In the following section of this chapter I explain how a 'conceptual funnel' (Marshall & Rossman 2006, p. 30) influenced my decision to study a specific topic in end of life and bereavement.

I realised that there was already a significant body of knowledge attending to caring for a person dying and the state of bereavement; however, it seemed that the transition period overlapping both these areas received little attention. What appeared to be lacking in the existing research literature were people's experiences of caring for someone who has died in the privacy of their own homes (Donnelly, Michael & Donnelly 2006; Woodhouse 2005). I considered that caring had to continue in the site of the home, at the same time that the acute sense of loss marked the death. I believed that the knowledge generated from this study could contribute to the small existing body of research and inform social work practice. A critical focus to my research question was the need to hear the accounts from people who had actually lived the experience.

The Key Research Question

The key research question in this study asks:

What are people's experiences of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness?

Enmeshed in the key question are two subsidiary questions, casting light upon other critical facets of the research. They are:

- What do people emphasise in their stories about attending to the death and final arrangements of a significant other person who died at home from a life limiting illness?
- What insights and wisdom emerge from people's stories of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness?

The following section of this chapter explains how I made sense of the terms within the research question so that these questions reflect qualities of simplicity, concreteness, specificity and clarity (Moustakas 1990, p. 41).

Terms of Reference

People

People who contribute to the medical, social, economic, environmental, spiritual and emotional needs of other people who are either fully or partially dependent, are often referred to as carers (Anderson, Anderson & Glanze 1998, p. 276). In the research question I have employed the collective noun of *people* to represent all persons who had an experience of attending to the death and final arrangements of a significant other person.

The term *people* is chosen for its inclusive quality. Alternative terms used throughout the research literature will often include *informal carers* (Rose 1999; Thomas, Morris & Harman 2002); *family caregivers* (Hudson, Aranda & Kristjanson, 2004; Rabow, Hauser & Adams 2004); *lay carers* (Donnelly, Michael & Donnelly 2006; Field et al. 1995); *care-givers* (Schulz & Beach 1999; Singer et al. 2005); *families* (Grbich, Parker & Maddocks 2001; Hudson 2003); *loved ones* (Keeley 2007); *companions* (Thomas, Morris & Harman 2002) and *hidden patients* (Kristjanson & Aoun 2004). For all these people, their actions are not governed by a workplace and the provision of care is located in the private space of the home (Phillips 2007, p. 22). These people usually refer to the person in receipt of their care as being their lover, partner, ex-partner, wife, husband, sister, brother, mother, father, daughter, son, grandmother, grandfather, relative or friend. Alternatively, if care is provided by a workplace either in the site of the home or an institution and the work is 'paid, and formally organised, regulated and monitored' (Phillips 2007, p. 22), the person who contributes to the needs of another is identified as a formal carer. Formal carers will usually refer to the person in receipt of their care as being their client or patient.

The research literature recognises that not everyone providing care identifies as a carer (Henderson 2001; Thomas, Morris & Harman 2002). The title of Henderson's (2001) article 'He's not my carer – he's my husband' indicates the tensions operating in the construction of identity, not only for the person providing the care but also for the person receiving the care. Henderson (2001 p. 149) explains that:

The development of informal care as a concept and informal carer as an identity has largely ignored the relationship in which the care is experienced.

The terms *family* and *family caregivers* may also exclude people who have no familial relationship to the person who has died, including close friends or acquaintances. These terms also have the potential to exclude people in same-sex relationships, particularly where governments fail to recognise their union. All of these terms are problematic, reductionist and potentially offensive (Phillips 2007, p. 23); however, their application is widespread and it is understood that there is 'no ideal substitution' (Thomas, Morris & Harman 2002, p. 531).

Experience

Experience is defined as being 'direct personal participation or observation' (Collins English Dictionary 1979, p. 514). Through the process of memory, recall or reflection, the nature of experience is conceptualised and ascribed meaning (van Manen 2001, p. 36). People rely on their ability to communicate experience through a variety of human constructions (Schwandt 1994, p. 129) such as dialogue, personal correspondence, photography, theatre, painting and blogging.

Attending

The concept of attending refers to the experience of being present for someone. This term suggests an awareness of another person's needs, implying a readiness for action and a close physical proximity, but in the specific context of this study does not necessitate the actual witnessing of the moment of death.

Death

The definition of death has been blurred in recent times, becoming 'increasingly complicated with varying and sometimes conflicting interpretations arising from differing disciplinary approaches, especially in the disciplines of law, theology, biology and in the clinical disciplines' (Martinson & Neelon 1994, p. 124). A biological death was once viewed as being the cessation of the functioning of vital organs including the heart, lungs and brain, but modern technology has enabled the functioning of some vital organs to the exclusion of others, hence the term *brain dead*. In these cases no brain functioning is observable but oxygen is delivered to human tissues by means of a mechanical ventilator. Legal death is defined as 'the total absence of activity in the brain and central nervous system, the cardiovascular system and the respiratory system as observed and declared by a physician' (Anderson, Anderson & Glanze 1999, p. 447). For the purpose of this study, death is defined as 'the cessation of life as indicated by the absence of heartbeat or respiration' (Anderson, Anderson & Glanze 1999, p. 447) and the observer understands the person to be no longer alive.

Final Arrangements

The term *final arrangements* is used to describe activities associated with the care of a human body in the event of death. Bern-Klug defines the term to mean ‘the collection of decisions made regarding body disposition, final ceremony and memorialization’ (Bern-Klug 2004, p. 31). The five constituents of final arrangements are identified as being: the disposal of the body; the type of ceremony to mark the passing of the life; merchandise for the disposal and or the ceremony; professional services with the disposal and/or ceremony; and methods of memorialising the life (Bern-Klug, Ekerdt & Nakashima 1999, p. 246).

Significant Other Person

Significant other person is a term referring to someone who has a personal attachment to another individual. The term is not synonymous with having an intimate relationship with someone and neither do people have to live together. The relationship may or may not be harmonious. The term is vague and extensive enough to encompass any relationship existing in the private sphere in which a person of any age is important or influential in the life of the other. Therefore a significant other person may be a child, sibling, lover, friend, relative, ex-partner, spouse or acquaintance.

Home

Home is a concept which embodies different meanings for different people (Annison 2000; Easthope 2004; Mallet 2004). Whereas notions of place, space, feelings and identity have been used as salient features to define the term, most researchers agree that the term is subjective. Mallet (2004, p. 84) explains that the definition is dependent upon the ‘broader historical and social context’ in which the term is located.

For the purpose of this study, home is defined as a place identified by someone to have the following attributes: it must be a physical space having a sense of belonging and connection and it must contain objects and possessions which symbolise comfort and familiarity. A home must be free from external surveillance whereby a person can exercise control over daily activities and social interactions. It must also represent a

place to which one has a desire to return. This study does not include residential homes or aged care facilities, although it is understood that many residents regard these places as their home. Their exclusion is based on the premise that people's activities are supported and monitored by workers who are bound by the governance of working rules and conditions. It is of no relevance to this study whether people own or rent their home.

Life-Limiting Illness

The term *life limiting illness* may be used interchangeably with the terms *life threatening*, *palliative* or *terminal*. This research employs the term *life limiting illness* to describe a wide range of diseases that prematurely end a person's life. Some examples include cancer, motor neurone disease, HIV/Aids, chronic renal failure and diabetes. These diseases are characterised as having no known cure although treatment may be available for pain and symptom management. A diagnosis of a life limiting illness implies that death is a natural progression of the disease in the foreseeable future.

Concluding Comments to Stage 1

This first stage of my heuristic enquiry has identified my interest in the field of death and bereavement. Borne from a deep desire to know how people experience the death and final arrangements of a significant other person who died at home from a life limiting illness, this research intends to illuminate and explicate new discoveries which will enable me to 'see and understand in a different way' (Moustakas 1990, p. 11). The following section of this thesis attends to the second stage of the heuristic enquiry, immersion.

Stage 2: Immersion

The immersion process enables the researcher to come to be on intimate terms with the question – to live it and grow in knowledge and understanding of it ... virtually anything connected with the question becomes raw material for immersion, for staying with and for maintaining a sustained focus and concentration (Moustakas 1990, p. 28).

Having established the research question ‘What are people’s experiences of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness?’, the next stage of this enquiry demands a thorough exploration of the phenomenon under investigation. The second stage, immersion, comprises two chapters: the literature review, and the research methodology and research methods. By examining and critiquing the knowledge already established within the research literature, I am confident that this study can go some way towards developing a broader understanding of end of life issues operating in the community. The immersion stage also provides a comprehensive description of the influential approaches and theories driving this research for the purpose of discerning the underpinning philosophical assumptions. The final section in this stage documents the research methods, highlighting the data collection and the style of analysis.

Chapter 3: Literature Review

Introduction to the Chapter

In this chapter I argue that there are three dominant themes encoded within the discourse of a home death resulting from a life limiting illness. These themes have been identified as:

- caring for a person who is dying
- caring for a person who has died
- grief associated with an expected death at home.

Each of these themes is examined to highlight their salient issues. Prior to the examination of how and where people die, the current landscape of late modernity is reviewed, providing a context for where death is situated in cultural, political and social systems of contemporary western society.

Death and Late Modernity

In western culture the period of late modernity began in the latter half of the twentieth century. The cultural dimension operating within this period is characterised by changes in ‘urban life, industrialisation, wealth, democratisation, science and technology’ (Webb 2006, p. 27). Uncertainty and change characterise this time, exhibiting ‘a rise in a secular individualistic culture ... marked by increased differentiation between people’ (Webb 2006, p. 27.) Innovation and technological advancement are given primacy over tradition, family members rarely live in close proximity to one another, and the rights of the individual through self-determination, autonomy and personal choice have become imperatives in people’s lives (Webb 2006, p. 27). To position matters of death within this context, Legge (2008, p. 22) explains that in making funeral arrangements, ‘church rituals will be snubbed in favour of secular memorial services for a generation reared on science and self-expression’. The personalising of funeral proceedings can be explained

in terms of the diminishing influence of religion evidenced by a 'decline in church attendance, membership, full-time professional clergy and use of sacraments' (Kellehear 2007b, p. 198). Though religion may no longer be regarded as the central authority in the period of late modernity, Rumbold (2006, p. 36) maintains that spirituality continues to play a significant role in people's lives, particularly at end of life. In the current climate of individualism, competition and greed, Rumbold (2006, pp. 35 - 36) claims that the central authority of the self rather than religion, gives rise to people reflecting upon 'the mystery of the human spirit' and ones 'unique individual identity' expressed through a diverse range of existential and experiential movements.

A faith in logic and science rather than a traditional faith in God has become a popular means to explain and control problematic people and situations (Camilleri 1999, p. 27). By employing scientific tools of assessment, prediction, causation and intervention, Webb (2006, pp. 4-8) explains that people believe they can reduce and control most risks and hazards operating in their daily lives. Such judgements rely heavily upon expert knowledge from dominant professions in society, such as medicine, to guide or determine what is a risk, how a risk can be measured and what risks should be prioritised (Kenny 2005, p. 50; Webb 2006, p. 19). This perspective is widespread, permeating much of people's decision making (Kenny 2005, p. 50). Emanating from the worldview of 'calculative reasoning' is the propensity to use binaries and dualisms which have become popular means to distinguish what is 'good' or 'bad'. This can be demonstrated in the desire of most people living in contemporary western culture to experience a good death. It can also be used to explain how grief is labelled as 'normal' or 'abnormal'.

Working alongside the widespread belief that risks can be managed is the political influence of advanced or neo-liberalist governance. Webb (2006, p. 16) explains that neo-liberalism is a 'set of political programmes and economic policies' which have emerged in western culture in the last twenty five years. Neo-liberalism is symbolised as economic market rationality, demonstrated through:

the rule of the market; cutting public expenditure on social services and reducing the safety net for the poor; de-regulating systems that diminish profit; privatising public enterprises and eliminating the concepts of the public good and of community replacing them with those of individual responsibility and choice (Webb 2006, p. 17).

To exist in this political framework means that individuals who assume personal responsibility for potential problematic situations are rewarded for being independent and self-reliant. Not planning for such events means that people may become dependent upon or directed by other people, including regulatory systems. A consequence may be that people have to relinquish some, or all, of their agency in the process. Pre-planning a funeral ahead of need is one example of trying to minimise certain risks, some of which may include preventing disagreements between individual family members and ensuring that money is spent in accordance with individual preference. Nominating an enduring guardian and an enduring power of attorney are other ways that people seek to control circumstances at end of life. Advance care planning is an attempt to have individual choices respected, even when a person can no longer communicate. The following section of the literature review now attends to caring for a person who is dying, shedding light upon the social factors influencing how and where people die in contemporary western society.

Caring for a Person who is Dying

How People Die

In the nineteenth and early twentieth centuries the most common death related causes, other than war, could be attributed to acute infectious diseases such as pneumonia, smallpox, tuberculosis and typhus (Bern-Klug, Gessert & Forbes 2001, p. 39; Najman 2000, p. 22). People's disease progression was usually swift and characterised by an obvious decline in health (Najman 2000, p. 25) with pain and symptom management restricted to unsophisticated resources, along with little expectation that dying would be pain free. Death was a familiar experience to people of all ages (Kissane 2000, p. 53) and when expected, was usually experienced in the site of the home (Bern-Klug, Gessert & Forbes 2001, p. 42; Kissane 2000, p. 53), most often in the bedroom surrounded by the company of other family members.

The research literature on end of life has discovered that how and where people die has radically changed throughout late modernity. The rate of child and infant mortality has

significantly been reduced (Kissane 2000, p. 53), evidenced by old age replacing infancy for the first time in history as the most probable time of death (Jalland 2006, p. 196). This change has been largely due to the innovations of antibiotics and immunisation, along with improved living standards (Najman 2000, p. 32). The introduction of cardiopulmonary resuscitation, blood transfusions, anaesthesia, surgery and public health has also helped to reduce the rate of mortality (Ashby 2007, public lecture). One offshoot from these developments has meant that people living in contemporary society now expect to have longer life spans than their predecessors.

In economically advantaged countries, disease related deaths are now largely attributed to life limiting illnesses which persist for longer periods of time in comparison to diseases borne from an acute nature (Bern-Klug, Gessert & Forbes 2001, p. 39). People are now more likely to be diagnosed and to be aware of the prognosis of their disease (Najman 2000, p. 33). Life limiting illnesses are progressive in nature, causing either partial or full disability (Najman 2000, p30). In some instances after diagnosis, an individual's functions will decline rapidly and death may occur within a period of less than two months. Alternatively, chronic disease can exist for a substantial period of time throughout a person's life, for months, years and perhaps even decades, whereby symptoms persist and become more complex (Najman 2000, p. 33). The changing nature of how people die has impacted upon where people die and this aspect will be examined in the following section.

Where People Die

Since the 1960s the subject of where people die has received considerable interest amongst researchers from varying disciplines, including the fields of: geography (Brown & Colton 2001); nursing (Tang 2003); clinical medicine (Higginson, Astin & Dolan 1998); psychology (Martineau, Blondeau & Godin 2003) and social science (Field & James 1993). Throughout the 1990s, this topic became a predominant focus of end of life research, at approximately the same time that home-based palliative care was integrated into mainstream services. The subject of where people die continues to attract interest, with the spotlight predominantly focused upon the sub-themes of preference of

place (Higginson & Sen-Gupta 2000; Tang 2003; Thomas, Morris & Clark 2004; Townsend et al. 1990); disparity between preferred and actual place (Beccaro et al. 2006; Hunt 1997; Tang & McCorkle 2003); factors predicting a home death (Bruera et al. 2002; Foreman et al. 2006; Gomes & Higginson 2006; Grande et al. 1999) and the perspectives of caregivers who support a person to die at home (Appelin, Broback & Bertero 2004; Brazil et al. 2005; Grinyer & Thomas 2004; Jones, Hansford, & Fiske 1993; Singer et al. 2005; Stajduhar et al. 2008; Stajduhar & Davies 2005). Each one of these sub-themes will be examined to demonstrate how the different dimensions of where a person dies contributes to the overall phenomenon of caring for a person dying from a life limiting illness.

Preference for Place of Death

When people have been questioned where they would prefer to die, the research literature is unanimous in its claim that the majority of people living in western society would prefer to die at home (Dunlop, Davies & Hockley 1989; Higginson & Sen-Gupta 2000; Tang 2003; Thomas, Morris & Clark 2004; Townsend et al. 1990). Statistics for preference of site of death are similar throughout the majority of western countries. A study from South Australia (Foreman et al. 2006), discovered that 70 percent of 2 652 respondents aged 15 years and older, from a broad socio-economic background, chose home as their preferred place of death. These statistics are reflected in other studies in which the scope of research includes:

- populations of adults with a prognosis of less than a year, diagnosed with terminal cancer (Townsend et al. 1990);
- young adults, 18 to 25 years of age, living with cancer (Grinyer & Thomas 2004);
- healthy young adults (Kastenbaum & Normand 1990);
- healthy older adults (Meyer 1998);
- parents of children and parents of young adults with life limiting illnesses (Goldman 1996; Grinyer & Thomas 2004); and
- people living with amyotrophic lateral sclerosis/motor neurone disease (Moore 1993).

One disruption to the data is evident in populations of older people who wish to die in a hospital or hospice because they feel safer in the company of trained staff (Gott et al. 2004), often motivated by the belief that their chances of survival would be increased (Fried et al. 1998).

The majority of the research has studied preference of site of death for people diagnosed with cancer. Weitzen et al. (2003, p. 324) suggest that this focus may be due to the dying trajectory being more predictable for people with cancer than other life limiting illnesses, although Vachon (1998, p. 49) highlights that this is dependent upon the type of cancer, as people with prostate or brain cancer are less likely to die at home. When stating a preferred place of death, Hay et al. (1999, p.9) found that people put conditions on their preferences, including pain and symptom management, functional control and burden to families. These findings support the research (Higginson & Sen-Gupta, 2000; Thomas, Morris & Clark, 2004) highlighting the complex and multidimensional nature of preference for place of death.

The research on preference of place of death is complex because people's preferences for where they would like to die changes over time, particularly in the final days of life (Hinton 1994; Townsend et al. 1990). Tang (2003) highlights the possibility that peoples' preference for place of dying and preference for site of death may in fact be different. It has also come to light that the preference for place of death for people who are dying may not be the same as for those who are their primary caregivers (Brazil et al. 2005; Stajduhar et al. 2008; Stajduhar & Davies 2005). Higginson and Sen-Gupta (2000, p. 299) elucidate the complex nature of preference of place of death, stating:

A preference for home care of death may be an empowered expression of wishes or an aversion from the perceived disadvantages of hospital care. A preference for hospital or hospice care may indicate a resigned acceptance of the inevitability of inpatient care, a desire to save relatives and close friends from the burden of caring at home, a belief in better care being provided or a refusal to admit that a cure is not possible. Many other interpretations are possible.

The factors shaping preference for place of death have been investigated by a number of writers. Thomas, Morris and Clark (2004) classified thirteen factors into the following

four key themes: the informal care resource; management of the body; experience of services; and experiential perspectives. The thirteen factors are:

1. Person's social network and living arrangements;
2. Person's assessment of the carer's capacity to care;
3. Person's concern for the welfare of the carer/family;
4. Carer's attitudes and willingness to care;
5. Symptom management;
6. Person's fears of loss of dignity;
7. Person and carer perceptions of the reliability of services and the degree of 'safety' they offer;
8. Person's attitude to a hospice;
9. Person's experience of hospitals;
10. Person's knowledge and experience of community services;
11. Person's attitude to nursing homes;
12. Person's attitude to and outlook on death and dying, including religious faith; and
13. Previous personal experience of death and dying (Thomas, Morris & Clark 2004, p. 2438).

A small body of researchers (Beresford, Adshead & Croft 2007; Donnelley, Michael & Donnelley 2006; Jivoff et al. 1979; Wheatley & Baker 2007) have recognised that workers' attitudes can affect people's choice of site as shown in the following comment:

As with many decisions made by families about post-hospital care, attitudes of hospital-based physicians, nurses, social workers and others may profoundly affect their choice (Jivoff et al. 1979, p. 7).

This is a neglected area in the main body of research literature, although its influence has been recognised more recently in a study focusing upon the interface between palliative care, social work and service users:

Professionals intervening in people's lives at vulnerable times can exert significant power over service users (Beresford, Adshead & Croft 2007, p. 64).

Research has shown that when offered a choice, most people living with a life limiting illness prefer to die in their own home, yet for a constellation of reason, the majority of

people will not achieve this goal. The disparity existing between preferred and actual place of death will now be examined in relation to caring for a person who is dying.

Disparity between Preferred and Actual Place of Death

Despite articulating a preference to die at home, most people with a life limiting illness will actually die in a hospital, hospice or aged care facility (Hunt 1997; Tang & McCorkle 2003). Brazil et al. (2005, p. 492) claim that 'the proportion of those who actually die at home ranges from 28 to 47 percent in industrialised countries'. These figures are reflected in Tang and McCorkle's (2003) study which indicated that only 29.9 percent of respondents died in their preferred site, and from statistics gathered by the Tasmanian Palliative Care Service which recorded only 31 percent of registered clients dying at home in the period between 2002 and 2003 (Eager et al. 2004, p. 64). An added dimension involving the disparity between preferred and actual place of death is the trend for people to relocate to hospital or hospice in the final month of life. Hinton (1994) found that approximately 90 percent of the care people receive in the last twelve months of their life occurs at home, but in the days nearing their death, people show a propensity to relocate to an acute care setting or hospice. This finding is reflected in other studies throughout the western world (Howat, Veitch & Cairns 2007; Sahlberg-Blom, Ternstedt & Johansson 1998).

The discourse on preferred and actual place of death identifies several salient features: first, people's preferences for site of death changes throughout their disease trajectory; second, the predominant focus by governments to move death into the community may not be in accordance with people's changing preferences and third, a death at home cannot be regarded as a 'gold standard' for everyone. Since a core philosophical principle operating throughout Australia's Palliative Care Standards (PCA Standards 2005) is to direct service delivery in accordance to the wishes of the person dying, it may be necessary to review people's preferences as they live their dying because their preference does not remain static. Rather than site of care being the most important aim, Bircumshaw (1993) believes that the experience of the person and his/her carer, should

impart greater significance, giving strength to the claim that preference for site of death needs to be reassessed throughout a person's dying trajectory.

Only recently has the research literature given recognition to the disparity existing between preferred and actual place of death by considering the tensions operating between patients, primary carers and professionals. Wheatley and Baker (2007) identified that there are people who want to leave inpatient facilities to return home to die; however, facilitating their discharge and sending them home would be unethical. This raises the dilemma that while home may be the preferred option, it may not be a realistic option for some people living in vulnerable situations. Examples of such cases may include an elderly person living alone with a rapid onset of dementia, or a person living in an isolated region with a debilitating mental illness whose primary carer has recently been admitted to hospital with a stroke.

The research literature investigating preferences for location of death has also identified a disparity between people who are dying and their family caregivers. A study undertaken in Canada (Stajduhar et al. 2008, p. 87) found that 'patients and their family caregivers agreed only about half the time on where the patient should die' and that only half of patients and their family caregivers reported a preference for a home death. This last finding is significant because it deviates from the main body of research which claims that the preferred option for site of death is the home. In the following section examining where people die, the factors forecasting a home death are examined.

Factors Forecasting a Home Death

Throughout the end of life research, several key areas have been identified which predict increased probability for a home death. Howat, Veitch and Cairns (2007) have chosen patient characteristics, carer characteristics and health service provision, as the three main themes to distinguish determinants of home death. These will be used to group the broad range of factors which increase the likelihood for people to die at home.

Characteristics of patients which enhance the reality of a home death include:

- being a male (Carlsson & Rollinson 2003; Foreman et al. 2006; Gomes & Higginson 2008; Higginson, Astin & Dolan 1998; Howat, Veitch & Cairns 2007; Jordhoy et al. 2000; Karlsen & Addington-Hall 1998);
- being aged under 65 years of age (Foreman et al. 2006; Gomes & Higginson 2008; Higginson, Astin & Dolan, 1998; Howat, Veitch & Cairns 2007; Karlsen & Addington-Hall 1998);
- being married (Gomes & Higginson 2006; Howat, Veitch & Cairns 2007; Jordhoy et al. 2000);
- living with a primary caregiver (Gomes & Higginson 2006; Jordhoy et al. 2000);
- having an additional carer to the primary caregiver (Dudgeon & Kristjansen 1995; Fukui et al. 2003; Visser et al. 2004);
- having a keen desire to die at home (Fukui et al. 2003; Gomes & Higginson 2006; Breura et al. 2002);
- having a diagnosis of certain types of cancer or AIDS (Gomes & Higginson 2008; Weitzen et al. 2003);
- having adequate financial resources (Grande, Addington-Hall & Todd 1998); and
- being involved in advanced care planning (Tang & McCorkle 2003).

Characteristics of carers which enhance the prospect for a home death include:

- being a female (Howat, Veitch & Cairns 2007) and
- being healthy, willing and able to provide care (Breura et al. 2002; Peruselli et al. 1999; Tang & McCorkle 2003).

Health service provision which enhances the prospect for a home death includes:

- access to community nursing (Howat, Veitch & Cairns 2007; Karlsen & Addington-Hall 1998);
- access to a general practitioner (Brazil et al. 2005; Yuen et al. 2003);
- access to palliative/hospice home care services (Grande, Addington-Hall & Todd 1998; Jordhoy et al. 2000; Karlsen & Addington-Hall 1998; Tang & McCorkle 2003); and

- access to specialised equipment, such as a hospital bed; commode; syringe driver or oxygen concentrator (Howat, Veitch & Cairns 2007; Karlsen & Addington-Hall 1998).

Conversely, the population for whom death at home is less likely to occur includes: women, elderly people, people who live alone, those who have little knowledge or understanding of community resources, and those whose pain and symptom management is uncontrolled. The research literature has also identified that the closer in proximity a person lives to a hospice, together with the availability of a bed, the higher the chances of dying in a hospice (Kessler 2005; Pritchard et al. 1998).

While home may be regarded as the most preferred site for death amongst many people in society, Seale (1995, p. 381) highlights that a death at home is not the ideal location for everyone and may be regarded as an unfortunate event if the person dies alone without community support. Seale's research (2000, p. 923) has also highlighted the current trends impacting upon households in economically advantaged countries, indicating a trend for a 'decreasing family size and a growing propensity of elderly people to live in households separate from their children', thereby illuminating the 'consequences of these changes for the sources of informal help and care that people could draw upon as they approached death'. Seale (2000, p. 924) recognised that people who were living alone were at risk of receiving limited support from the community. He noted that:

They were the least likely to have any children or siblings alive and were most likely to be widowed or divorced or old. They were also the group most likely to progress to institutional care (Seale 2000, p. 924).

Perspectives of Carers

The research literature has firmly established that the probability of dying at home will be increased if the care is provided by family members or close others who live with the person dying (Dudgeon & Kristjansen 1995; Fukui et al. 2003; Gomes & Higginson 2006; Howat, Veitch & Cairns 2007; Jordhoy et al. 2000; Visser et al. 2004). The

concept of care is open to wide interpretations (Phillips 2007, p. 14). When referring to the care provided by family members or close others, care encompasses an action or an attitude, or a combination of both (Phillips 2007, p. 15). Care that involves the giving of one's self for the well-being of another identifies with the ethics of care approach which regards the value of the caring relationship to be 'in its potential for compassionate ethical reciprocity' (Webb 2006, p. 210). Van Manen (2002) asserts that 'care-as-worry' 'may be experienced as a complex moral-emotional relation of responsibility' (van Manen 2002, p. 268). This dimension of care appears to have received little recognition in the experiential accounts of caring in the research literature. Frohm (1984 orig. pub. 1957, p.28) proposes that care is one essential element of the art of loving, also involving responsibility, respect and knowledge; however, the research into domestic and family violence throughout end of life (Fisher 2003) demonstrates that not everyone providing care is doing it from a position of love.

In a study which explored caring for people who are terminally ill, Rhodes and Shaw (1999, pp. 40-41) identified eight features which although not exclusive to terminal care, distinguish this particular type of care as having a distinctive character. These features include: being a time-limited activity; experiencing progressive loss; involving processes of disclosure and awareness; adopting medicalisation of the home; enlisting formal support; dealing with issues affecting continuity; making decisions about place of death and facing ongoing bereavement issues. Sinding (2003, p. 153) has also studied the nature of the end-of-life care experience from the perspectives of informal carers and suggests that care can be 'shaped in particular ways by an awareness of approaching death'. In the body of research literature attending to caring at end of life, the topic which has received the greatest attention involves the associated risks involved with caring:

Family caregivers by nature of the work they do are at serious risk for physical, social and financial burdens as a result of caring for a dying family member at home. Chronic fatigue, physical exhaustion, sleeplessness, burnout and deterioration in their own health are among the physical burdens commonly experienced by family caregivers. Social burdens including restrictions on time and freedom, disruption of personal routines and leisure activities and role conflicts associated with having to balance the needs of the sick with those of well family members have also been documented. In addition, many caregivers experience income loss as a result of time lost from work to provide care for an ill family member (Stajduhar & Davies 1998, p. 10).

The stressors and challenges arising from financial, emotional, physical and social burdens have been thoroughly documented (Mastrian, Ritter & Deimling 1996; Navaie-Waliser et al. 2002; Palliative Care Australia 2004; Stajduhar & Davies 1998), with growing recognition given to the support needed by informal carers if they are to remain as the cornerstone of future caring arrangements (Aoun et al. 2005; Proot et al. 2003; Rhodes & Shaw 1999). A death at home is recognised as being a challenge for families (Sankar 1993; Stajduhar & Davies 1998). Jones, Hansford and Fiske (1993, p. 250) have identified that 'most carers themselves experienced physical symptoms during the terminal illness'.

Deteriorating health and co-existing conditions have given rise to some researchers identifying carers as the 'hidden patients' (Kristjanson & Aoun 2004). Carer fatigue, financial, social, emotional and physical burdens, inadequate home services and the need for pain and symptom control have been the key reasons identified for admission into a hospital or hospice (Brazil et al. 2005; Thomas, Morris & Clark 2004; Visser et al. 2004). Sankar (1993, p. 61) highlights that few carers throughout the illness trajectory are prepared for the 'extreme fragility of the dying person' with subsequent feelings of anguish and fear. Vachon (1998, p. 53) highlights how witnessing a dying relative's perceived suffering results in carer distress and feelings of helplessness. Hinton's study (1994) found that as a dying person's health deteriorated, caregivers began to doubt that the home was the best site for their relative to die, thereby re-assessing their decision and changing their preference to the site of the hospital. The research also demonstrates that when a dying person is admitted into a hospital or hospice there may not be an end to the carer's stress. Visser et al. (2004, p. 474) state that caregivers:

may experience feelings of guilt or failure because they had to hand over their role as primary care provider to institutional caregivers. However, following admission, caregivers continue to provide care and remain committed to their relatives, although their tasks change. Placement then shifts, rather than eliminates the caregiver burden.

Despite home being identified as the most popular preferred place of death, the research has also discovered that the majority of bereaved caregivers were satisfied with their final

place of care, regardless of whether it was the home or hospital. In a South Australian study, Wakefield and Ashby (1993, p. 534) found:

Most caregivers considered that the place of death was the right place for the patient to have died. Home deaths were characterised by the patient having expressed a wish to die at home, whereas institutional care was sought because it was perceived that there would be better control of problematic symptoms in the terminal phase of care.

More recently, similar results have been detected in a Canadian study which states that:

most informal caregivers (93%) reported in retrospect, that where the care recipient died was the right place regardless of the stated preference of the care recipient. (Brazil et al. 2005, p. 494).

While the role of caring for a person with a life limiting illness has received much attention in the research literature, the greater focus of enquiry has been on the dying trajectory (Main 2002) and only recently have the positive aspects of caring for a person been identified (Brown & Stetz 1999; Cohen, Colantonio & Vernich 2002; Grbich, Parker & Maddocks 2001; Hudson 2004). In Hudson's study (2004, p. 60), 60 percent of the caregivers interviewed were able to identify beneficial aspects of caring for a dying relative at home, citing family closeness, the emergence of strengths and a greater purpose in life as positive outcomes. Grbich, Parker and Maddocks' study (2001, p. 35) reports similar findings of positive outcomes, citing 'the gift of time and the pleasure of being given the opportunity to communicate one's love and to show affection through care'. A study undertaken by Singer et al. (2005, p. 73) on caregivers' perspectives of home death found that:

Positive outcomes and reduction in negative outcomes appear to be dependent upon availability of adequate support systems to meet both physical and emotional needs.

What becomes apparent from the research is that the issue of the carer warrants attention, because carers can significantly impact upon people's place of death (Rhodes & Shaw 1999; Stajduhar et al. 2008; Stajduhar & Davies 1998; Tang & McCorkle 2001; Visser et al. 2004). The most recent research, however, finds that carers:

are not always involved in this decision nor are their preferences for location of death equally considered to that of the patient (Stajduhar et al. 2008, p. 85).

Another study found that:

Family members may be ambivalent about providing home care but often do so based on the wishes of the dying person and sometimes feel they have little choice in the decision-making process (Stajduhar & Davies 2005, p. 21).

The findings from the above mentioned study (Stajduhar & Davies 2005) grouped family members' decisions for palliative home care into three categories, namely: uninformed, indifferent and negotiated. Uninformed decisions were usually made with little thought as to what it would mean to undertake the role of carer. Indifferent decisions were often made because people felt they had little agency in the decision making, often complying with the preference of the person dying. Negotiated decisions for home care were made when carers and their significant other person spoke about the future and came to a mutually agreeable decision. This study also found that decision making was based on three critical factors, including:

fulfilling a promise to the patient to be cared for at home, desiring to maintain a 'normal family life' and having previous negative encounters with institutional care (Stajduhar & Davies 2005, pp. 26-28).

The conclusion in their study, supporting the body of research on caring for a dying person is encapsulated in the following statement:

Given the complexity of the home care environment when palliative care is provided there and given that each family shares a history that determines, to a large extent, how family members will cope with the physical and emotional demands of home care, there can be no 'universal' rule to determine whose choices ought to be respected when decisions for palliative home care are made. However, in the context of the home, where decisions have immense impact on family caregivers, consideration of caregivers' needs ought to be central to the decision-making process (Stajduhar & Davies 2005, p. 30).

This section of the literature review has studied how and where people die in contemporary western society. An examination of the literature on preference of place of death; disparity between preferred and actual place of death, factors predicting place of death, and the perspectives of carers relating to place of death has illuminated two anomalies. First, many people living in economically advantaged countries prefer to die at home, yet for a constellation of reasons, they die in an institution, either in a hospital, hospice or aged care facility. Second, most people live their dying at home, yet relocate

to a hospital or hospice in the final days of their life when the inevitable outcome of death cannot be averted. Many factors play a role in determining where a person will die and only recently have the considerations of carers been addressed in the research literature. In the following section of this literature review, three other influences on caring for a person who is dying will be explored: the medicalisation of death, the avoidance of death and the ideology of a good death. This literature offers further insight to the complexity of caring for a person who is dying.

The Medicalisation of Death

Given that the majority of people in the western world are now dying in acute care settings, Aries, in his seminal research on the changing social attitudes to death throughout the ages, declares that the hospital had achieved 'a local monopoly on death' (1981, p. 584). He adds that in the modern world death had become the 'triumph of medicalisation' (Aries 1981, p. 583). The term 'medicalisation' is commonly used to depict the negative influences that modern medicine exerts upon death and dying, and is usually applied in a pejorative context throughout the sociological, biomedical and psychological literature (Clark 2002, p. 905).

Aries' views were shared by the German philosopher Illich (1976), renowned for his attack upon the medicalisation of death. Illich's critique was based upon his belief that people's health had been seized by medical specialists and that individuals had become 'pathetically dependent' (1976, p. 111), unable to accept death and suffering as meaningful aspects in their life. Without medical presence, Illich believed that death was 'synonymous with romantic pigheadedness, privilege or disaster' (1976, p. 108). He claims that hospital death was endemic and that the monopoly that medicine held was a form of social control (1976, p. 51). He further claims that people feared an unmedicated and unhygienic death at home (1976, p. 109), believing that hospitalisation would increase their chances of surviving a crisis (1976, p. 112).

In general, critics of medicalisation employ the argument that the excessive use of technology to either prolong life or defeat death gives little regard to the quality of

people's lives (Clark 2002; McCue 1995). Zimmerman and Rodin (2004, p. 124) note that 'technology is only limited by technical constraints with a lack of moral restraint on the part of the clinical caregivers'. What emerges as a key theme throughout the literature on the medicalisation of death is that the medical imperative of cure is privileged above the care of the dying person (Zimmerman & Rodin 2004, p. 124).

The technical advancements in medicine and the increasing numbers of elderly people have given rise to the phenomenon of the dying process being ambiguous (Bern-Klug 2004; Bern-Klug, Gessert & Forbes 2001; Kellehear 2007b). Kellehear (2007b, p. 211) claims that there has been an 'erosion of awareness of dying' which 'makes the task of identifying the onset of dying extremely difficult'. Kastenbaum and Kastenbaum (1989, p. 103) highlight the complex nature of dying, providing insight how the process is understood to have various meanings, and citing six different interpretations of when dying begins. These dimensions include:

- as soon as a person is born;
- at the beginning of a fatal condition;
- when a fatal condition becomes recognised by a doctor;
- when a person is informed by their doctor of the fatal condition;
- when the person realises and accepts the diagnosis; and
- when a cure is unavailable.

Ellershaw and Ward (2003, p. 30) highlight the difficulty for clinicians to diagnose dying, stating that it is a complex process which can be impeded by numerous factors, such as: disagreement about the patient's condition; poor ability to communicate with the patient and family; fear of foreshortening life; and failure to recognise crucial symptoms and signs (2003, p. 31). The ambiguous nature of the moment of death is further highlighted by Kastenbaum (1999, pp. 256-257) who highlights the differences between people's observations and interpretations, further complicated by the propensity for people to transfer their own feelings, values and expectations onto others seeing 'something they hope or fear to see'. Kastenbaum also draws attention to the different spiritual interpretations of the moment of death (1999, p. 259) as well as the 'fallible criterion' that the moment of death can be defined as synonymous with the dying person taking their last breath.

Another interpretation of the ambiguity of death can be found in the ways that medical and pharmacological technologies effectively disguise the process of dying for the purpose of alleviating pain and symptom management. McNamara (2001, p. 120) raises the question of whether palliative care masks pain or masks death, and if it is the latter, then palliative care fails to accept death. This line of reasoning is reflected in Lewis's (2007) study of medicine and the care of the dying:

'Palliative' is derived from the Latin for cloak or mantle 'pallium'. Metaphorically, palliative care may be seen as a cloak of warmth and protection for the terminally ill. Robert Twycross, a British pioneer of hospice, has used the term in another way: the symptoms are 'cloaked' with treatments whose only aim is to make the patient comfortable (Lewis 2007, p. 121).

Clark and Seymour (1999, p. 119) caution critics to use the term 'medicalisation' wisely. Their argument claims that while attending only to the negative features of medicine, the alternative view of being able to recognise the benefits that medicine offers to those who are dying is neglected. Connelly (1997-1998) shares this opinion, recommending that the 'medicalisation of the dying has the potential for dramatically improving patient care, rather than curing'. Medical technology and appropriate pharmacology can be instrumental in serving a person's best interests throughout their dying trajectory.

Twycross (2002, p. 272) states:

clinical experience suggests that those whose pain is relieved live longer than would have been the case if they had continued to be exhausted and demoralized by severe unremitting pain.

The Denial of Death

Another dimension identified throughout the research literature on caring for a dying person is the denial or avoidance of death. These terms are associated with the medicalisation of the dying process and the segregation of the dying to hospitals, hospices and aged care facilities. The trend to relocate death from the home into public facilities was studied by the sociologists Glaser and Strauss (1965) in the latter half of the 20th century. Their studies interpreted the event of relocating to an acute care setting as death loomed closer as one of delegating or surrendering responsibility to medically

trained personnel for the purpose of overseeing the dying and death of people with life limiting illnesses.

Aries (1974, 1981) claims that death became institutionalised because the modern attitude to death is that it is dirty, invisible, denied and 'banished from daily life' (Aries, 1981, p. 27). Aries argues that 'the truth' of death has been occluded by a 'lie' caused by 'an important physical phenomenon; the displacement of the site of death' (Aries 1981, p. 87). Zimmermann and Rodin (2004, p. 125) claim that the medicalisation of death is depicted by the segregation of dying people in hospitals and in the treatment of death as a 'technical matter'. This view is supported by McNamara (2001) who attributes, in part, the predominance of deaths occurring in hospitals to the nature of chronic illness:

The implications of dying reliant on technology and therapeutic successes of medicine have meant that most people in contemporary western societies die in hospital or in other institutional settings like nursing homes ... the reason people mostly die in institutional care can be partially explained by the increase in chronic illnesses which often necessitate medical care (McNamara 2001, p. 73).

Three other theorists studying death in society (Aries 1981; Elias 1985; Kubler-Ross 1969) maintain that segregation has been a dominant force operating in end of life, causing solitude, loneliness and dehumanisation. Aries states:

The dying man's bedroom has passed from the home to the hospital. For technical reasons, this transfer has been accepted by families and popularized and facilitated by their complicity. The hospital is the only place where death is sure of escaping visibility – or what remains of it – that is hereafter regarded as unsuitable and morbid. The hospital has become the place of solitary death (Aries 1981, p. 571).

The argument that modern death is forbidden, sequestered, denied and taboo, was popularised throughout the mid to late 20th century by influential writers such as Gorer, (1955), Blauner (1966), Kubler-Ross (1969), Becker (1973), Aries (1974, 1981), Illich (1976), Elias (1985) and Mellor and Shilling (1993). In the mid 1950s, the British anthropologist Gorer (1955) published an essay titled 'The Pornography of Death'. He claimed that 19th century society regarded both birth and sex as taboo topics but throughout the 20th century there was a shift in prudery and death usurped their place. Gorer believed that people had come to regard natural death as obscene, shameful and unmentionable. In a reprint titled 'Death, Grief and Mourning' Gorer (1965) examined

rituals of mourning which he believed were disappearing due to a rising tide of secularisation. Gorer suggested that 'we give back to death, natural death, its parade and publicity, readmit grief and mourning' so that society could resist the 'modern pornography of death' (Gorer 1965, p. 199). More than half a century onwards, the argument is extended by the Australian sociologist Kellehear (2005, 2003) in his plea to bring death and dying back into the public arena for the purpose of promoting public health.

There are a variety of ways that theorists have interpreted the denial of death. In contrast to Gorer's argument, the American anthropologist Becker (1973) believes that the fear of death, referred to as a 'terror', is defined for the purpose of 'self-preservation' (1973, p. 16). He claims that:

the idea of death, the fear of it, haunts the human animal like nothing else: it is a mainspring of human activity – activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny of man (Becker 1973, p. ix).

Becker believed that people denied death by unconsciously repressing any thoughts of mortality, therefore denial of death was considered to be the human condition and was instrumental in the survival of human life. From a sociological perspective, Giddens (1991) claims that people's ontological security is threatened by the prospect of death, so that for social order to continue, people need to avoid 'fateful moments', thereby denying death. Elias (1985, p. 10) believes that death and dying are topics too confronting for people to contemplate because '... another's death is a reminder of one's own'.

A common theme found throughout the literature on end of life is that death is perceived as a 'highly threatening construct' (Evans, Walters & Hatch-Woodruff 1999, p. 718) and that people find ways to 'protect themselves from the disturbing realities of their deathbed scene' (Evans, Walters & Hatch-Woodruff 1999, p. 718). Evidence to support this claim was demonstrated by a study of American students enrolled in a death education course, who were asked to consider their own deathbed scenes (Kastenbaum & Normand 1990). For these young adults, death was anticipated in the context of old age, supported by family and friends in the location of their own home, free of pain, and transpiring quickly (Kastenbaum & Normand 1990, p. 206). Despite being introduced

throughout their studies to the ways in which most people die in contemporary western society, students conceptualised their death in desired ways rather than what was most likely to happen, thereby supporting the claim that death is a highly threatening construct.

The theory of death denial has operated in tandem with the theory of acceptance. Kastenbaum (1987-1988, p. 408) argues that throughout the 1980s, the terms *denial* and *acceptance* had 'long attained the status of thanatological buzz words'. As it has already been established in the research literature, death in the modern world has been centrally located in the hospital, hospice or aged care facility and the assumption made that people denied their death by removing it from their own private space of the home into the setting of an institution, but the research literature emanating from the sociological and allied health fields (Kellehear 1984; Seale 1995; Telford, Kralik & Koch 2006; Zimmermann 2004) challenges the denial of death thesis. Kellehear (1984) argues that western industrial societies are not death denying. His argument is based on five salient points, those being: the use of the term *denial*; the fear of death; the medicalisation of death; the twentieth century crisis of individualism and examples of death-denying social practices. In the first instance, Kellehear believes that the application of the term *denial* is value-laden (1984, p. 714), used indiscriminately (1984, p. 713) and with unknown accuracy (1984, p. 714). He further highlights how it is applied inappropriately in sociological analysis because it is 'psychiatric in origin' (1984, p. 714). Jalland (2006, p. 20) supports this claim, stating that users of the term *denial* need to be clear about the context in which it is applied because different fields of disciplines interpret their meanings differently. In the second instance, Kellehear distinguishes between the fear of death and the fear of dying, explaining that:

people do fear death but this fear is not universal. Psychologically, much of this fear of death may be more accurately understood as a fear of dying' (Kellehear 1984, p. 715).

In the third instance, Kellehear debunks the notion that modern society is death denying through the influence of medicalisation:

The medicalisation of death has not transformed our general view into one that denies its impact, or its existence or its 'sting' as it were. Medicalising death has meant the transformation of the dying role into a low status, technology intensive and potentially contaminating situation in need of sanitising. Death has been re-interpreted but the new interpretation is not denial (Kellehear 1984, p. 717).

In the fourth instance, Kellehear argues that death denial is portrayed in the research literature as being synonymous with the absence of a 'good death' (1984, p. 717). The ideology of a good death is examined in greater detail in the following section of this chapter, but a key principle in the argument of a good death is that a person has the ability to exercise autonomy. However, Kellehear (1984, p. 718) points out that medical innovations have enabled citizen autonomy because 'although death now occurs mostly in hospitals, the longer part of dying may still be carried on at home or even at work'. In the final argument used by Kellehear to challenge the denial of death thesis, some examples of social practices are highlighted. Previously in this chapter, it was mentioned that Gorer (1955) believed that people avoided speaking about death and dying. Kellehear highlights that the practice of not discussing death 'does not stem from death denial, but aspirations for smooth relations and conduct', which have emanated from:

conversational propriety and emotional reserve ... applied meaningfully to a range of awkward and ambiguous topics and situations (Kellehear 1984, p. 719.)

Some researchers have also highlighted the pejorative application of the term *denial* in the biomedical context of illness (Telford, Kralik & Koch 2006; Zimmermann 2004), identifying the reasons for its common usage and how the application by professionals potentially promotes negative outcomes for people. Telford, Kralik and Koch (2006, p. 458) argue that:

the concepts of acceptance and denial have been 'authored' by a scientific way of thinking and have been constructed as 'legitimate' markers in understanding individual responses to chronic illness. These labels may be internalized, contributing towards a damaged sense of self and constraining the efforts to re-establish a valued self identity.

Zimmermann considers the politics of the term *denial*, highlighted in the following statement:

Rather than being a defence mechanism at the level of individual psychology, denial can be seen as an instrument in a larger discourse on dying which both invites patients to participate in the planning of their death and labels those who do not comply (Zimmerman 2004, p. 1778).

The following section examines the research literature surrounding the ideology of a good death. What becomes evident from examining the literature is that integral to the changing patterns of death and dying is a co-existent change in people's expectations concerning death.

A Good Death

A *good death* has also been referred to in the literature on end of life as an *appropriate death* (Weisman 1972), an *easeful death* (Morgan 1996), *dying well* (Byock 1997) and a *death with dignity* (Roy 2000). Although the literature differs in its criteria for what constitutes a good death (Wallerstedt & Andershed 2007, p. 32), the mainstay of the definition involves a death characterised as quick, painless, at home and surrounded by loved ones (Meyer 1998, p. 1). Clark (2002, p. 907) broadens these criteria by adding 'open acknowledgement of the imminence of death; an "aware" death, in which personal conflicts and unfinished business are resolved; and death as personal growth'. A common theme throughout the various interpretations indicates that people want an approach to death which is autonomous, individualised, without suffering and experienced in the privacy of one's own home.

The term *good death* is problematic because it is value-laden, operates as a binary and implies notions of absolute and universal truths. How a good death is defined will be determined by the dominant discourse in a social and cultural context (McNamara 2004; McNamara, Waddell & Colvin 1994; Walter 2003) but variations of deaths in the context of a complex society mean that no one particular good death can be essentialised for all (McNamara 2004, p. 929). The ideology of a 'good death' is used as common currency in contemporary western society, setting up an impossible standard which assumes everyone can achieve a good death if all the risks are predicted and managed efficiently.

Many want dying to be an experience that can be characterised as 'good' yet persons near death and those who care for them often perceive it as difficult or painful, harrowing or humiliating. People want death to be made comfortable by the tools of medicine which they expect can eliminate both the disturbing visible signs of the body's disintegration and the patient's experience of suffering ... many want to control the way death happens for themselves and their loved ones by planning ahead for it, yet few are actually prepared for the moments when

decisions must be made or for the kinds of questions that will emerge when death is near (Kaufman 2005, p. 4).

McNamara (2004, p. 930) believes that palliative care practitioners work towards:

a good enough death for their patients because autonomy and choice are compromised by a return to routine medical practices and a hierarchy of care, which prioritises the physical management of symptoms.

Palliative care, palliative medicine and the hospice movement are instrumental in promoting the ideology of a good death, thereby playing a significant role in the way that people understand the construct (McNamara 2001, p. 135). Palliative care is defined by the World Health Organisation as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation 2002).

Palliative care, palliative medicine and hospice can be distinguished from one another (McNamara 2001, p. 121). Palliative care is provided both as a specialty and throughout mainstream services, although in mainstream services, the term *palliative approach* is used to distinguish this care from the care offered by specialists in an interdisciplinary team. As a specialty, palliative care emphasises symptom management which largely employs medicine as the main source to alleviate people's suffering (Twycross 2002, p. 271). In palliative care, the interdisciplinary team is made up of doctors, nurses, social workers, pastoral care workers, occupational therapists, physiotherapists, music therapists, volunteers and a variety of other people, although the configuration of each team will vary according to available resources. Palliative medicine has been recognised as a medical specialty since 1987 (Twycross 2002, p. 271) and generally refers to the:

study and management of patients, with active, progressive far advanced disease for whom the prognosis is limited and the focus of care is the quality of life (Doyle, Hanks & MacDonald 1993, p. 3).

McNamara (2001, p. 121) explains that in contemporary society, the term *hospice* is used most commonly in relation to an inpatient facility, which employs palliative care for end of life. Doyle, Hanks and MacDonald (1993, p. 5) claim that 'In the west, palliative care is coming to be seen as a basic human right when curative care is no longer possible'. Palliative Care Standards espouse patient autonomy and consumer choice as core principles to guide service delivery, the aim being to empower people who are dying and their families. This objective is evident in Standard One, which states:

Care is based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, caregiver and family needs and wishes are acknowledged and guide decision-making and care planning (Palliative Care Australia 2005).

Empowering people by allowing them to make their own end of life decisions is integral to Palliative Care Standards; however, Kaufman (2005) highlights the tensions operating between people's expectations and the actual experience of dying, giving weight to McNamara's theory of providing a 'good enough death' (McNamara 2004).

Kastenbaum and Normand (1990) have highlighted the disparity between the expected death bed scene and the death bed scene experienced in real life, calling for a review of 'the structure and dynamics of actual death bed scenes and their relationship to our expectations, fears and hopes' (Kastenbaum & Normand 1990, p. 216).

The expected death bed scene almost always runs a simple and predictable course. Once the scenario is set in motion, it tends to follow its course in a coherent manner. By contrast, the death bed scene in real life situations often breaks into new directions or changes in character in ways that the participants had not expected (Kastenbaum & Normand 1990, p. 215).

Kellehear (2007b, p. 191) believes that in the context of the 'cosmopolitan age', a good death was superseded by a well-managed death, characterised as:

an increasingly private affair shared with small groups such as the historically evolved small family, a few work friends and a coterie of trusted professionals visiting the home or working at the local hospital (Kellehear 2007b, p. 149).

Kellehear (2007b, pp. 210-211) argues that dying in the cosmopolitan age is not actually well-managed because together with 'an erosion of awareness of dying' has been 'an

erosion of support for dying', demonstrated through the neglect of people dying from AIDS, the elderly in nursing homes and people living in poverty. He believes that 'long dying does not necessarily create good deaths or well-managed ones any more', (Kellehear 2007b, p. 207) giving rise to 'the birth of the shameful death' (Kellehear 2007b, p. 213). A death is shameful because these populations are stigmatised by dominant groups in society and segregated so that their plights remain unnoticed, thus enabling the community to relinquish responsibility for their care. Kellehear (2007b, p. 251) summarises his thesis by stating:

the experience of dying has gradually become more private at the same time as its recognition has become more publicly controlled and defined.

The research literature has identified an escalation of the public's demand for palliative care due to changing trends in society (Eager et al. 2004; Evans & Walsh 2002; Roy 2000). It is anticipated that government and health care resources will be stretched beyond their ability to supply palliative care to all those in need (Eager et al. 2004, p. i). This is a salient reason for the concerted effort by governments to promote informal care. Without the support of informal carers, governments recognise that their goals to provide end of life care in the community will be thwarted. But Roy (2000, p. 898) cautions that 'dying at home is by itself no guarantee of dying with dignity'. He claims that:

Palliative care in the home cannot work without the allocation of social resources needed to train sufficient numbers of professionals able to give families competent, timely and continuing assistance. Without the dedication of resources and without that assistance, home care will come to little more than a deceiving promise (Roy 2000, p. 899).

The research findings have recognised the practice implications for health care providers and policy makers. To increase the chances of achieving a preferred option of death, the research literature makes three recommendations and acknowledges the shortfalls impeding people's wish to die in the manner they prefer. First, the provision of high level communication from health care workers for people who are dying in the presence of their primary caregivers, is regarded as a critical factor to improve understanding of what is available to support people's choices in end of life (Beccaro et al. 2006, p. 415).

Discussing where and how people want to die may be subjects neglected by some health care professionals (van den Eynden et al. 2000, p. 62) and it may be:

...hindered by the very difficult challenge of prognostication and bad news breaking at a time when patients are particularly vulnerable and are trying to remain hopeful as they begin new treatment for their disease (Bruera et al. 2002, p. 2127).

Ratner, Norlander and McSteen (2001 p. 780) support the need for ongoing assessment and dialogue with patients and their families, promoting the use of advance care planning: 'a term used for the process of preparing for likely scenarios near the end of life' (Ratner, Norlander & McSteen 2001, p. 778). Their proposal regards the environment as an important feature in effective communication, suggesting 'a kitchen table discussion' in the home with the person who is dying in the company of other family members, and promotes the role of the social worker to guide the process (2001, p. 779). A social worker is recommended because the style of communication is based on an ethical framework emphasising individual social and cultural contexts, relationships, and open, honest communication rather than the transfer of information. Beccaro et al. (2006, p. 415) maintain that ongoing dialogue is needed so that workers can accurately check people's preference for place of death given that people change their ideas about where they would like to die over the course of their disease trajectory. McCarron (2000, p. 25) explains that:

...even when the decision to stay at home is made, some discussion is necessary early in the regimen about the option of hospital or hospice admission if circumstances change.

Second, the knowledge of, access to, and the supply of adequate resources are essential to making the preferred place of death a reality. Nurses who visit the home are considered to play a pivotal role in enabling a death at home (Howat, Veitch & Cairns 2007; Karlsen & Addington-Hall 1998), providing information, reassessment of a person's changing health status, drug administration, support and reassurance to carers. Kessler et al. (2005, p. 109) discovered that the difficulty in accessing a bed in a hospital or hospice was a significant barrier to people wanting to die in an institution, stating that:

Many felt misled into believing a hospice bed would be available for them and as with the provision of health and social services care, had no understanding of the criteria by which resources were allocated.

Third, education about death and dying is needed not only for the general community, but community nurses, general practitioners (Hays et al. 1999, p. 18) and all other workers involved in the care of the person dying. Kellehear (2003, p. 30) endorses the idea that palliative care should exist as a unit of public health given that the language in public health is simple, accessible and positive. He believes that death education should be for everyone (2003, p. 32) and should be promoted as part of community development (2003, p. 33) through such practices as a poster campaign and short story competition (2003, p. 34). His rationale for bringing palliative care into the public arena is based on the belief that it will strengthen 'personal and community resilience to living with dying, grief and the burden of care' (Kellehear 2003, p. 34).

The preceding section of the literature review has examined the various dimensions in contemporary society which help to shape the general experience of caring for a person who is dying. The research literature identifies the struggle between what people expect and what people actually experience, by identifying the relevant social factors operating within a landscape of late modernity. Ideals of individualism, including citizen rights, personal choice, control and decision making, all collide with politics of institutionalisation, segregation and medicalisation, ultimately creating a general feeling of unease about what can reasonably be considered a good death. Critics have recently suggested that a good death exists only in the rhetoric, requiring significant ongoing support from a diverse range of supports and resources within the community to bring the concept into existence. In the following section of this literature review, caring for a person dying at home from a life limiting illness is examined in the context of people's experiences in the final days and hours leading up to and including the moment of death.

End of Life

While the 'management of the final days of life is a recurring issue in the palliative care literature' (Peruselli et al. 1999, p. 234), my attempts to locate empirical research from the perspectives of carers in the hours close to death generated few results. This was surprising because Fenwick, Lovelace and Brayne (2007, p. 322) recognise that many carers are 'finding themselves in the role of the new priests at the bedside'. My discovery is supported by Kastenbaum (1999) who identified the notable absence of research attending to the moment of death. Kastenbaum (1999) questions why the hospice movement has not contributed to this 'highly charged moment in time' (1999, p. 255), 'given its philosophy, its staffing by people of faith and the long history of religious attention to the end-of-life drama' (1999, p. 264), claiming that:

the intensely subjective character of the moment of death has no place in the objectivistic frame of discourse with which hospice and all other human service organizations must function (Kastenbaum 1999, p. 261).

In the following section of this review I examine a small yet authoritative body of research which explores caregiving at end of life. I highlight findings on pain and symptom management and pay attention to the paranormal experiences witnessed by carers as death approaches. I begin by reviewing a selection of qualitative studies showing the salient issues emerging from this body of literature.

In Brown and Stetz's study (1999, p. 182) entitled 'The labour of care-giving', twenty-six family caregivers of people diagnosed with AIDS or advanced cancer were interviewed over a four month period. Four phases emerged throughout this study: involving becoming a caregiver; taking care; midwifing the death and taking the next step. Throughout the first two phases, carers coped with profound changes in their lives and assumed responsibility for new tasks. Feelings of inadequacy were common; however, carers developed competencies and developed expertise in their care-giving roles. The phase which surrounded the days and hours before the death was referred to as 'midwifing the death', and involved the themes of waiting and doing, and hoping for a good death (Brown & Stetz, 1999, pp. 191-192). In waiting and doing, caregivers 'seemed to function as gatekeepers, organising and regulating the care given and the

contact the dying person had with others' (Brown & Stetz 1999, p. 191). Feelings of helplessness were evident throughout this period. In a personal reflection by Breitbart (2006, p. 313) on the experience of waiting for the results from medical tests, he states that the experience of waiting implies 'a passive activity ... a state of physical inactivity and lack of forward movement' but 'nothing could be further from the truth'. When waiting operates in the context of impending death, as it does when waiting for medical results, it exists as '... a state of physical, mental and emotional turmoil that knows no equal in human experience' (Breitbart 2006, p. 313). This observation supports Brown and Stetz's study which discovered that people throughout the phase of waiting and doing often experienced exhaustion (Brown & Stetz 1999, p. 191) and a heightened sense of awareness. The other theme throughout the phase of midwifing the death was identified as hoping for a good death. Brown and Stetz (1999, p. 192) discovered that in this phase people felt a responsibility for maintaining the dying person's comfort and managing all of the required resources:

Many felt that the ill person's quality of life during his or her final days and hours was a reflection of their competence as caregivers ... During this time, caregivers demanded a higher level of performance of themselves. They believed this was their last chance to 'do things right.' For many, this final caring was an ultimate expression of love (Brown & Stetz 1999, p. 192).

Sinding's study (2003, p. 156) of twelve people who cared for a family member or friend who died from breast cancer found that care-giving at end of life demonstrated 'an imperative quality' which included 'the imperative that relatives and friends provide care themselves and that the ill person not be left alone' (2003, p. 155). Sinding discovered that when carers were unable to meet end of life imperatives, they experienced distress which would sometimes evoke moral sanction (2003, p. 156.) Sinding's study (2003) also highlighted the anguish that carers experienced from witnessing the dying person's suffering, often prompting their pleas to end the life of the dying person.

Sometimes the entreaty to 'go' was spoken directly to the ill person ... more often, requests for interventions that would end consciousness or end the person's life were directed toward God and toward physicians. Carer's strong desires for the ill person's life to end – their negotiations for the ill person's death – emerged from a combination of awareness of her suffering and consciousness of their own pain (Sinding 2003, p. 161).

Staton, Shuy and Byock (2001, p. 287) also studied the last few months of life of people who had been diagnosed with a life limiting illness, together with the people who cared for them. They discovered that in the last days and final hours leading up to the deaths, several key features emerged as being distinctive of this particular type of caring, including '... issues of control, social networks, comfort and growth'. Carers persevered to maintain the dying person's preferences and to honour their wishes. Close family members and friends gathered, sometimes expanding the social network to include children and pets, and communication between the caregiver and the person dying offered opportunities for personal growth and enabling family unity and the making of meaning (Staton, Shuy & Byock 2001, p. 288).

Keeley's study (2007, p. 225) in which 'fifty-five people discussed their final conversations with a loved one who has since died', discovered five different types of messages in the final days and hours before death. The primary functions of these messages included:

- the confirmation of love;
- the altering and bolstering of identity;
- the validation of religious/spiritual beliefs;
- the maintenance of the relationship; and
- the stepping towards reconciliation. (Keeley 2007, pp. 234-245).

Keeley (2007, p. 245) realises that the expression of love was a priority for the participants as it confirmed their connection, and completed their relationship with the person who was dying and Meeker's study (2004, p. 204) which 'investigated decision-making experiences of twenty surrogates who assisted terminally ill family members', elucidated the key themes of caring and respect:

Much as providers sometimes struggle between honouring a patient's self-determination and acting beneficently, so too, did the surrogates weigh and assess the pull of these two primary values. Consideration of both care and respect characterised all of the surrogates reported activities in relationship to the ill family member. For most of the participants, care giving and decision making were inextricably linked (Meeker 2004, p. 210).

The major categories which Meeker (2004) identifies throughout her study 'Seeing them through with care and respect' are: learning the diagnosis; standing with; gating; acting for; taking leave and outcomes. 'Taking leave' is the final phase of 'Seeing them through', involving the sub-processes of 'knowing' (perceiving terminality), preparing for the death, and honouring the life. During this period, participants reported awareness of the impending death, although this did not always occur before the actual death (Meeker 2004, p. 219) and actions in 'preparing for death' happened in response to knowing that the death was about to occur.

Despite being located in the site of the hospital, Woodhouse's (2005) study is significant because it is a detailed qualitative account focusing on the time of death. Woodhouse's reflection (2005, p. 28) on sitting at the bedside of her dying father in the site of a hospital throughout his final hours of life enabled her to observe 'the family and health-care staff and reflect on the situation as a means of coping during this difficult time'. Woodhouse recorded a detailed account of what transpired in the final hours and at the moment of death, illustrating a scene which brought family members around the bedside to express their 'love and statements of goodbye' (Woodhouse 2005, p. 28) while closely observing the dying man's breathing, mouth and eyes. The signs of impending death were closely watched by family members, whose imperative was to witness the moment that death transpired, captured in Woodhouse's (2005, p. 29) statement that 'some chanced a toilet break'. When unable to discern a pulse, her father was pronounced dead. After the doctor certified the death, the family members remained clustered around the bed and consoled one another. Woodhouse (2005, p. 29) explains what happened in response to his death:

While an informant gained the written information on 'what to do next' from a member of staff, the others tidied up around the bedside and the overnight accommodation, removing all traces of the group's presence. Members of the family commented on the final appearance of Bert (handsome, peaceful) or the experience (beautiful, glad we were all there). There was a short time of indecision 'What do we [the group] do now?' followed by arrangements for disassembling. The majority of the family returned to their own homes, leaving the deceased in the care of the staff and the hospital's procedures (Woodhouse 2005, p. 29).

This reflection by Woodhouse (2005) highlights the social nature of death and drew attention to the health care workers who maintained a presence throughout the dying.

Like Thomas, Morris and Clark (2004), Woodhouse (2005, p. 31) also emphasises how witnessing a death can ultimately shape people's beliefs about death and dying.

In another qualitative study undertaken with ten families, several doctors working in palliative care sought to 'bring the deathbed scene to (their) clinical and conceptual attention' (Donnelly, Michael & Donnelly 2006, p. 352). The purpose of this study was to learn 'from witnesses about the experience of the moment of death (2006, p. 352). Donnelly, Michael and Donnelly (2006) acknowledge that doctors are rarely present at the moment of death (2006, p. 352) and that the lived experience can help identify the features in which health care support can be improved. Throughout this study, participants also gathered around the bedside, closely observing breathing (2006, p. 357). Two significant themes emerged. These included the relationships (2006, p. 358) between people, and the mystery of death (2006, p. 357).

The significance ascribed to the relationship between the carer and the person dying is evident in this field of literature, acknowledged by Sinding (2003, p. 157) as 'the value of closeness' and by Keeley (2007, p. 247) who claims 'that relationships are the most important thing at the end of life'. Meeker (2004, p. 222) also describes the journey for carers as 'arduous yet compelling', implying that the primacy of caring is located in the relationship between the carer and the person who was dying. Donnelly, Michael and Donnelly (2006, p. 355) ascertain that the moment of death is both 'very important to the carers,' and 'intimate' (2006, p. 364) whilst other researchers have linked the expression of love with caring (Brown & Stetz 1999; Sinding 2003).

In their study, Donnelly, Michael and Donnelly (2006) explored the role of the professional, discovering how professional surveillance has the potential to diminish the experience of the moment of death for people in their own homes:

There is a risk that we can as professionals disable those who are apparently untrained, captured in the phrase 'the tyranny of specialisation,' suggesting that the very 'excellence' of professional palliative care can disempower ... The professionals who act as unobtrusive guides, who disappear quietly from the intimate scene of dying, enable care at home (Donnelly, Michael & Donnelly 2006, p. 364).

This study is significant in that it defies the traditional view of expert knowledge having dominance over personal experience, thus addressing the factor of ‘source credibility’ proposed by Kastenbaum (1999, p. 262) as one reason why the moment of death has been neglected in the research literature. Donnelly, Michael and Donnelly (2006, p. 363) respond to the ideology of a good death and recognise the influence of professionals:

We do not claim that the ‘good death’ occurs in the home nor is only possible in the home. We do claim that the moment of death is very important to family carers. We suggest that, irrespective of the location of an anticipated death, the moment of death is highly charged and needs to be handled skilfully by the professional carer.

A recurring theme in the studies which focus upon pain and symptom management in the last days of life, highlights pain as a major concern for patients and carers (Addington-Hall & McCarthy 1995; Hanson, Danis & Garrett 1997; Ventafridda et al. 1990). This finding is significant because people rate freedom from pain as an imperative in their pursuit of a good death (Clark 2002; Meyer 1998; Singer, Martin & Kelner 1999; Steinhäuser et al. 2000). Peruselli et al. (1999, p. 237) found from their study, that while pain was relatively well controlled during the last days of life, other symptoms, such as dyspnoea, were more problematic. Another study investigating pain and symptom control explained that sedation is used predominantly in managing symptoms (Peruselli, et al. 1999). Hallenbeck (2005, p. 2267) also highlights how some symptoms experienced by patients, such as respiratory secretions causing noisy breathing, often referred to as the ‘death rattles’, create distress for the carer but not necessarily for the patient. Fear and the inability to stop pain and suffering were factors which caused considerable distress to carers.

In the last decade, there has been growing interest by researchers in paranormal experiences at end of life. Fenwick, Lovelace and Brayne (2007, pp. 316-318) describe several categories of paranormal phenomena known at end of life: deathbed visions; something leaving the body; deathbed coincidences; and dreams. Barbato (2005, p. 215) postulates the medical, psychological and transcendental reasons for these phenomena, stating that deathbed visions are not synonymous with hallucinations. This is supported by the findings of Fenwick, Lovelace and Brayne’s study which found that all

interviewees 'drew a clear distinction between end of life experiences and drug-induced hallucinations' (2007, p. 318).

Deathbed visions are commonly-reported end of life experiences and are usually regarded by a dying person as comforting (Barbato 2005, p. 214; Fenwick, Lovelace & Brayne 2007, p. 316) in contrast to the anxiety or fear experienced by the person witnessing the dying person's experience (Barbato 2005, p. 214). 'The perception of something leaving the body around the time of death' (Fenwick, Lovelace & Brayne 2007, p. 317) is understood to be the least discussed phenomenon with other people. Deathbed coincidences reported by a close companion include such experiences as the awareness of the person's death, clocks which have stopped at the time of death, and sightings of significant animals or birds (Fenwick, Lovelace & Brayne 2007, pp. 317-318). Dreams as part of end of life experiences are usually considered as a comfort, providing reassurance, both to the person having the dream and for the close companions (Fenwick, Lovelace & Brayne 2007, p. 319). Researchers in this field (Barbato 2005; Fenwick, Lovelace & Brayne 2007) are unanimous in their claim that end of life experiences should not be undermined, believing they warrant recognition for what is a real and meaningful part both of the dying process, for the person who is dying and for the person who witnesses the death.

In all of these studies on caring for a person in the days and hours before death, what clearly emerges are the challenges that carers had to face, ranging from dealing with fear, anxiety and exhaustion, to coping with family concerns, dealing with the health care system, and honouring the wishes of the person dying. Also evident throughout these qualitative studies is the personal growth and reward that carers identified from undertaking this care, bringing attention to the positive aspects of caring at end of life (Hudson 2006; Meeker 2004; Singer, et al. 2005). In the next section of this literature review, the theme of caring for a dead person is examined, highlighting the actions and attitudes of carers throughout the period of final arrangements.

Caring for a Person who has Died

Whilst the research literature on end of life has addressed carers' participation in funeral arrangements (Doka 1984-1985), predominantly in the context of how funeral participation influences grief adjustment (Gamino et al. 2000; Lensing 2001; Romanoff & Terenzio 1998), there appears to be few studies devoted to the care given to a person who has died specifically located in the site of the home. In the literature on end of life, care has been depicted as ending when the person has died (Barbato 2005, p. 209), as demonstrated in the following comment:

After death occurred, caring for the ill person ceased and study participants worked to bring closure to their care-giving roles (Brown & Stetz 1999, p. 192).

The disproportionate gap in the research literature given to the care of someone who is dying compared to the care of someone who has died may be due to the curative or healing focus embedded in the medical model. Apart from being used as a tool for research purposes or dissected for organ transplants, Lupton (1994, p. 45) proposes that a body devoid of life is of little use to the medical model. There is now a growing number of studies from the perspectives of doctors, nurses, chaplains and social workers, which attend to the care of a dead person. These studies have generally focused on care in hospitals and nursing homes (Berndt 2004; Ferris et al. 1998; Hodgson et al. 2004; Komaromy 2000; Quesed & Rudge 2003; Weber, Ochsmann & Huber 1998). These studies highlight the need for competence in dealing with the tasks performed after a death, and the associated duty of care in attending to patients and family members at the onset of bereavement. This interest may be due, in part, to the body of knowledge suggesting that bereavement outcomes are affected by a carer's perception at end of life (Grande et al. 2004).

Berndt's study (2004), based on the perspective of a chaplain in a nursing home, describes how attending to deceased residents gradually evolved from completing tasks quickly, such as the immediate cleaning up and transferring the body to a funeral home, towards a more relaxed and dignified approach bidding farewell of 'a valued member of the community' (Berndt 2004, p. 53). Berndt (2004, p. 54) states:

At the time of death, the family is invited to spend as much time with the resident as they need. If they were not present at the time of death, we invite them to come in before the body is removed if they wish. The bedside prayer service we have now is a simple, written ritual. After the service, the body of the deceased resident remains in the bed until people from the funeral home arrive. The final journey out of the home is not through a hidden exist to a loading dock but rather through an exit on the main floor – for a dignified departure. We offer family, staff and residents the opportunity to travel with the deceased resident in a departure procession (Berndt 2004, p. 54).

This particular study demonstrates how caring continues after death through the actions and attitudes of people in a professional capacity. Quested and Rudge (2003, p. 554) discovered from their study of nurses that ‘nursing care does not stop when a patient dies’, although how nurses mediate the transition from alive to dead is constrained and shaped by nursing procedure manuals. These findings are congruent with those of Woodhouse (2005) who found that the nursing staff had immediately attended to the procedures relating to her father’s death on the ward.

Pattison’s article (2008, p. 42) on the care given by nurses to patients who died, explained that ‘Consideration for the patient as a person should not cease simply because he or she died’. Pattison (2000, p. 48) further claims that ‘It is important to undertake all procedures at the end of a patient’s life with the utmost sensitivity since it is the last caring act for the patient and will be remembered by their family for years to come’. This supports the argument that manifested in the duties associated with the death of a patient is a professional duty of care, not only to the deceased person but to their significant others. This duty of care is addressed in McGrath’s study (2007) of Aboriginal cultural practices around caring for a deceased person. The practices highlighted throughout McGrath’s study include making time for family to spend with the deceased, wailing and crying, sorry camps and sending the body home to the community. This study focused attention on nurses’ skills of asking, listening and observing the post-death practices which hold significance to Aboriginal people, thereby recommending cultural competence. McGrath (2007, p. 425) states:

The central message is respect for the cultural difference situated in the humility of knowing that there can be many different cultural beliefs and practices that shape the human response to death.

In contrast to Berndt's study (2004) which made death a communal event, Komaromy (2000) found that people in residential and nursing homes were 'deprived of visual evidence' of a deceased person, yet there were 'no attempts to conceal the sounds associated with the departing corpse' (Komaromy 2000, p. 299). This study highlights the powerful need of some institutions to manage death in ways which attempt to protect people from the reality of death through hiding the physical presence of a dead body. Lunghi (2006, p. 38) believes that 'the body is the physical exemplar or referent for the abstract concept of death' and 'such rituals as viewing the corpse, preparing it, kissing the lips of the deceased, carrying the coffin and so on, have probably evolved to reinforce this reality'. Lunghi (2006, p. 38) adds, however, that throughout western societies the viewing of the body and other means of contact are no longer commonplace for people because the distancing from direct contact conspires 'with our disposition to deny death'.

Research by Davies (2005), which studied the needs of mothers to be with their dying child and their child's body after death, found a common theme of mothers wanting to have access to their child's body in the days transpiring after the death leading up to the funeral (2005, p. 295). Time, space and privacy spent with their deceased child was important for all of the mothers, offering opportunities to hold their child, take photographs, dress them in chosen clothes and hold private ceremonies. For the children who died in hospital, mothers found that their time 'was limited by the facilities available and the hospital routine' (Davies 2005, p. 295). Within hours of death, the child's body was usually transferred to a mortuary, suggesting that the actual site in which a child died significantly impacts upon the time, space and privacy available to mothers. It also suggests that all mothers visited their child at the funeral home after being transferred from the hospital, but found that they had to make an appointment to view their child and that the time allocated to be with their child was brief. One participant explained that in the site of the funeral home, she 'felt too inhibited to hold her daughter's body, a missed opportunity she regretted' (Davies 2005, p. 296). Another participant expressed anger that no one informed her that she was able to take her deceased child home from the hospital (Davies 2005, p. 297). This study highlights the role of the health care professional in enabling or disabling mothers their 'rightful place at the centre of care' (Davies 2005, p. 298), thereby reinforcing Baglow's (2007, p. 224) claim that 'the social corpse is imbued with presence and personhood'.

These studies stress the importance of care after death; however, there is evidence to suggest that some professionals, including doctors, are ill-prepared to provide this care. In 1996, a sample of 568 physicians in Germany, were asked to respond to a mail questionnaire regarding their knowledge of laying out and viewing a deceased person's body (Weber, Ochsmann & Huber 1998, p. 34). The three main findings from this study demonstrated that the majority of physicians were not familiar with the burial laws concerning laying out at home; that there was a general lack of interest amongst doctors in the events following the death; and the significant influence that doctors have on the tradition of laying out. The study drew attention to the responsibility of doctors in attending to matters following a death:

Taking account of the well-established relationship between the grieving process and morbidity, not to mention the mortality of the survivors, the commitment of a doctor to his or her patients even beyond death should be considered less as a remarkable voluntary act and more as a duty (Weber, Ochsmann & Huber 1998, p. 37).

Similar findings were revealed more recently by a physician (Hallenbeck 2005) whose research highlighted the different perspectives of families and clinicians dealing with a patient's death:

Care does not end with the death of the patient but continues through death pronouncement, family notification of the death, discussion of autopsy and immediate bereavement support (Hallenbeck 2005, p. 2265).

Hallenbeck (2005, p. 2268) believes that dealing with death is often relegated to interns 'who have little or no training how to do it skilfully'. These findings are further bolstered by an American survey of medical staff dealing with death (Ferris et al. 1998), highlighting how medical interns 'are regularly exposed to hospital deaths, yet report minimal training, wide variations in practice and significant distress with the performance of tasks after a death' (Ferris et al. 1998, p. 231). Furthermore, Grant (1997, p. 1035) found that doctors are needed 'to help educate the public and emergency services about how to respond after an expected death occurs at home'. This study argues that emergency response teams are often inappropriately called to deaths that occur at home, ultimately creating 'needless cost and needless worry'. It can therefore be argued that death is a neglected part of medical care training.

The research literature attending to the care of a dead person by significant others, specifically in the site of the home, is in short supply. Greater attention in end of life research has been given to the care provided by medical staff, funeral staff and the clergy, with outcomes highlighting the need for effective communication and ongoing dialogue with people who require their support following a death. In the next section, the subject of final arrangements as part of the care of a dead person is examined.

Final Arrangements

Final arrangements is a term first used in 1990 by researchers who studied the differences between burial and cremation as a means of body disposal (Dawson, Santos & Burdick 1990). The research on final arrangements has received attention from a small number of researchers studying end of life care. Bern-Klug, Ekerdt and Wilkinson (1999, p. 128) make the claim that research in the social sciences relating to helping people make final arrangements is 'practically non-existent'.

When making decisions regarding final arrangements, people are confronted with a large range of options (Bern-Klug 2004, p. 31; Sofka 2004, p. 23), providing greater flexibility, but at the same time creating ambivalence and frustration (Bern-Klug 2004, p. 31). Researchers suggest that available options should be discussed prior to the death to reduce stress, uncertainty and alleviate demands in early bereavement (Bern-Klug 2004, p. 33; Hallenbeck 2005, p. 2269). Bern-Klug (2004, p. 33) recommends that decisions should be made prior to death about:

- what will happen to the body;
- where the remains will be kept;
- what type of ceremony is needed to acknowledge the death;
- what merchandise is needed;
- how the merchandise will be acquired;
- what services are needed;
- how the services will be acquired;
- how and when expenses will be paid;
- how the deceased person will be memorialised and

- who will make the decisions.

Dawson, Santos and Burdick (1990, p. 129) identify eight factors influencing the choice between burial and cremation, for 'close survivors of deceased persons':

1. The preference of the deceased;
2. The preference of close survivors;
3. The cost of arrangements;
4. The social/community tradition;
5. The convenience/efficiency of arrangements;
6. The appearance of the body at death;
7. The deterioration of body after death; and
8. The concern for the use of land.

Bern-Klug (2004, p. 32) identifies a number of factors which have the potential to complicate the undertaking of final arrangements following a death: emotions; finances; the irreversible nature of decisions; the large number of decisions to be made; confusion regarding the purpose of the funeral or memorial; inexperience; and etiquette uncertainty. Sofka (2004, p. 21) also draws attention to the conflicts which can arise between family members, 'particularly in cases of long standing difficulties in relationships or differences of opinion about how to honour a person's life following the person's death'. A number of these studies have focused on how these factors complicate final arrangements.

Studies on funeral expenditure are sparse (Fan & Zick 2004, p. 38); however, the financial impact of death has been addressed by a number of researchers (Bern-Klug, Ekerdt & Nakashima 1999; Bern-Klug, Ekerdt & Wilkinson 1999; Corden, Sainsbury & Sloper 2002; Fan & Zick 2004) indicating how money matters encroach upon early bereavement. Corden, Sainsbury and Sloper (2002, pp. 130-131) have highlighted how the costs of care and the costs of death have long-term financial effects for families when a child dies, thereby adding stress to parents' decision making in early bereavement. Fan and Zick's (2004, p. 39) research proposes that 'typically funeral and burial decisions are made under considerable time and emotional pressure' and recommend that 'advance planning with regards to funerals and burial arrangements, and the life insurance that

might be available to cover these costs, can reduce the potential economic burden' (2004, p. 52). Bern-Klug (2004, p. 31) echoes a similar sentiment, adding, 'If these decisions are made after the death, the decision maker can be at a disadvantage'.

Lensing (2001, p. 49) highlights that the post-death ritual of the funeral has four purposes for people, including the physical goal of removing the deceased, the social goal of providing support for the mourners, the psychological goal of assisting mourners to accept the reality of the death and the religious goal of offering perspectives on the issues of life and death. This analysis is supported by Dawson, Santos and Burdick (1990, p. 131) who explain that the funeral 'serves the important functions of providing some form of public recognition that a death has occurred, providing a framework in which to support those most affected by the death and disposing of the body'. Gamino et al. (2000, p. 91) found that 'funeral rituals appeared to enhance mourners' comfort at the time of death both by facilitating social support and by connecting the griever with deeper levels of meaning with which to understand and frame their loss experience'. This particular study also identified how funerals can transpire in unexpected ways for mourners. Gamino et al. (2000, p. 79) discovered from seventy-four participants' experiences, forty three percent of mourners reported 'some type of negative event or distressing outcome had occurred during the funeral service' (2000, p. 84). These outcomes were grouped into seven categories:

- conflicts among survivors;
- issues with cremation;
- decedent's wishes versus survivors wishes;
- state of the body;
- problems with the funeral home;
- problems with the minister and
- financial problems. (Gamino et al. 2000, pp. 84-87).

A common theme evident in the studies of final arrangements is the need for the bereaved to make decisions with many other stakeholders in mind, including family members, the deceased, and people with whom the arrangements must be made such as the clergy and funeral directors. Parsons' (2003, p. 84) study of funeral directors and conflict in the context of care identified several areas which have the potential to generate tensions,

including: 'the economic environment of funerals; the contractual relationship between the funeral director and client; control of the funeral and the funeral director as agent between the bereaved and third parties'.

The previous sections of this chapter have examined the research literature relating to how people experience the death and final arrangements for a significant other person who died at home from a life limiting illness. The two key areas distinguished from the research were caring for a person who is dying, and caring for a person who has died. The findings from the research highlight the complex nature of death in contemporary society, demonstrating how social factors play a critical role in the way that death is negotiated. In the next section of this literature review, the theme of grief is explored, specifically in the context of attending the death and final arrangements of a significant other person who died at home.

Grief Associated with an Expected Death at Home

This section of the literature review examines grief associated with an expected death at home. The time marked by an acute sense of loss in which caring must continue is eclipsed by a prevailing interest by the medical field in the potential risks of bereavement. Operating alongside this dominant discourse is a much smaller yet compelling body of research literature identifying positive outcomes during bereavement. Before examining the literature, it is worthwhile defining grief and bereavement. These terms are often used interchangeably; however, I argue that they are distinct concepts with different meanings.

Defining Grief

The term *grief* refers to a person's response to the loss of something significant (Goldsworthy 2005, p. 173; Weber 2001 p. 48). Grief will always involve a loss of some sort; however, not all losses will precipitate a response of grief (Weber 2001, p. 21). It is the meaning or significance that a person ascribes to the loss which determines the scope

of a person's grief (McKissock 1999, p. 318; Weber 2001, p. 16). Grief and loss are intrinsic to people's lives (Goldsworthy 2005, p. 171) and grief is experienced uniquely by each person (McKissock 1999, p. 317; Weber 2001 p. 49). Dimensions of a person's life which can be affected by grief include the physical, social, emotional, psychological, cognitive, spiritual (Moody & Arcangel 2001, pp. 32-33) and paranormal (Moody & Arcangel 2001, p. 162).

Several different types of grief have been identified in the research literature including *anticipatory grief* (Worden 1987); *disenfranchised grief* (Doka 1989); *complicated grief* (Prigerson & Maciejewski 2005-2006) and *good or normal grief* (Weber 2001).

Anticipatory grief refers to 'grieving that occurs prior to the actual loss' (Worden 1987, p. 92). This may include mourning the loss of future events or milestones in a person's life. *Disenfranchised grief* is a term coined by Doka (1989, p. 4) to describe 'the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported'. This particular type of grief has also been referred to as 'gagged grief' (Green 2008) and 'silenced grief' (Todd 2007).

Complicated grief is described in greater detail further in this chapter. It is considered a unique disorder in which the severity and duration of symptoms will lead to a diagnosis.

Good or normal grief is considered a natural response to the loss of something significant (Weber 2001).

Factors which influence a person's grief include: cultural norms; spiritual, religious and philosophical beliefs; a person's age; their stage of development; their gender; a history of major depression; previous experience of loss, and the type of loss experienced (Kristjanson & Lobb 2004, p. 57; McKissock 1999, pp. 318-322). Examples of events which may precipitate a response of grief include: the loss of workplace employment; the breakdown of a relationship; the removal of children by state intervention; and the loss of home through political persecution, natural disaster, poverty or cultural invasion. Death is also an event which can precipitate a response of grief and people can experience death personally or indirectly by means such as observing death on the television or in the cinema; reading reports documented in newspapers or attending another person's death. People can die from events in a number of ways including: a car accident, drowning or electrocution; suicide; murder; corporal punishment; war; terrorism; death in custody;

miscarriage; sudden infant death syndrome; euthanasia; and ageing. In the context of this literature review, death is encountered through the means of a life limiting illness.

Defining Bereavement

Bereavement is a term inextricably linked to a person's death. Stroebe and Schut (1998, p. 7) describe bereavement as 'the situation of a person who has recently experienced the loss of someone significant through that person's death'. In the research literature attending to bereavement, people who had a personal relationship with the person who died are sometimes referred to as 'survivors' (Keeley 2007). Attig (2004, p. 343) describes bereavement as a 'state of deprivation, not a reaction or response'. The duration of bereavement seems to be ambiguous (Goldsworthy 2005, p. 173), although it appears that theorists and health professionals connect the temporal dimension of bereavement in the context of what is considered as being 'normal' and 'abnormal' grief. Mourning is often associated with bereavement. The term *mourning* refers to 'the social expression or acts expressive of grief, which are shaped by the practices of a given society or cultural group (Stroebe & Schut 1998, p. 7). Consideration of the variables between cultural and social practices in different communities helps to illuminate the complexity of mourning.

Traditional Theories of Grief and Bereavement

There are a growing number of researchers who approach matters of mortality in alternative ways to traditional practice, demonstrating that the complexities of death and bereavement can no longer be captured by any one perspective alone (Kastenbaum 1987-1988; Kellehear 2007a). Some theorists claim that contemporary society is experiencing a 'revival' of death (Lee 2002; Walter 1994), from what was once considered 'forbidden, invisible, dirty and indecent' (Aries 1981, p. 87). Others consider that late modernity has characterised death as 'a highly plastic, even elusive idea' (Kellehear 2007a, p. 72), requiring new ways of thinking and different approaches. In the following section, the traditional views of grief and bereavement are highlighted, helping to cast light on the prevailing interest in the phenomenon of complicated grief.

The idea that successful mourning is dependent upon people severing their ties with the deceased was promoted by the early work of Freud (1957, orig. pub. 1917) whose paper titled 'Mourning and Melancholia' sought to determine how grief differed from clinical depression. Freud has been criticised for claiming universal truth, providing no reference to any cultural or familial contexts (Hedtke & Winslade 2004, p. 22). Freud's work has, however, had significant influence on subsequent theorists in the fields of medicine, psychiatry and psychology.

The concept of normal and abnormal grief was promoted by Lindemann (1944) in his paper 'Symptomatology and management of acute grief'. Lindemann perceives acute grief as a syndrome which had predictable characteristics needing treatment and management by professionals who could restore health to the person suffering this particular disorder. Sensing the presence of the dead was just one of the symptoms which indicated an abnormal response to grief which he referred to as 'morbid grief'. Lindemann (1944) indicates a time frame of eight to ten weeks in which a therapist could expect the syndrome of acute grief to be resolved, but only through the means of appropriate intervention. Miles and Demi (1994, p. 89) point out that Lindemann's time frame had significant influence on a broad perspective that grief only lasts for a certain period.

Kubler-Ross (1969) initially postulated five stages to explain the process of dying and these phases were subsequently adopted as a theory of grief. These stages are the processes of denial, anger, bargaining, depression and acceptance; a sixth stage, hope was later incorporated into the model. The popularity of this model has been attributed to its simple step-by-step approach; however, Kubler-Ross (Kubler-Ross & Kessler 2005, p. 7) claims that the model was never intended to be viewed as progressing in a linear fashion.

Bowlby (1982) also later extended his developmental theory of attachment derived from studying how children separated from their mothers to incorporate the grief responses of bereaved adults. Throughout bereavement, the aim of successfully detaching from a deceased person was viewed by Bowlby as the means to achieve psychological adjustment.

Worden (1982) proposes four tasks of mourning, involving: the acceptance of the reality of the loss; the working through the pain of grief; the adjusting to an environment in which the deceased is missing; and emotionally relocating the deceased and moving on with life. This model clearly promotes the notion of breaking ties. Rando's (1992-93) theory identifies three phases — avoidance, confrontation and accommodation — in the grieving process, claiming there are six processes of mourning which need expression to achieve a healthy outcome. These processes include: recognising the loss; reacting to the separation; recollecting and re-experiencing the relationship with the deceased person; relinquishing the old attachment to the deceased and the old assumptive world; readjusting adaptively and moving into the new world without forgetting the old world; and reinvesting in other relationships.

Couched firmly within a mental health framework and primarily concerned with emotions, these theorists are criticised for being prescriptive and neglecting to address the cultural, religious and individual variations of people (Goldsworthy 2005, pp. 167-168). These theorists have also been credited with constructing bereavement as a process which moves towards an end point, thereby completing the 'work', 'phases' or 'stages' required for the psychological adjustment for letting go of the deceased. Littlewood's (1993, p. 73) riposte to this perspective is:

the stage/phase presentation may only ever make sense to people who have not experienced bereavement, eg, in all probability most young to middle-aged health care professionals in contemporary society.

The understanding of grief and bereavement from a mental health framework has been instrumental in the development and conceptualisation of the phenomenon of complicated grief which is perceived as a psychological disorder. The next section of this review attends to how bereavement is constructed as a risk within the field of biomedicine. A definition of complicated grief is provided, along with an overview of how it is distinguished by clinicians as deviating from normal or healthy grief, and alternative ways of understanding this phenomenon are highlighted.

Bereavement as a Risk

The risks of bereavement have been well-documented throughout the biomedical research literature, highlighting the propensity for people throughout bereavement to be at risk of decreased physical and mental health (Christakis & Iwashyna 2003; Germain et al. 2005; Kreicbergs 2005; Ott 2003; Prigerson, Maciejewski & Rosenheck 2000; Sheldon 1998), including heightened rates of mortality (Latham & Prigerson 2004):

Bereavement increases the risk of major depressive episodes and anxiety-related symptoms and disorders, and is a risk factor for impaired immune function, increased physician visits, poorer physical health, increased use of alcohol and cigarettes, suicide, and mortality from causes not restricted to suicide (Latham & Prigerson 2004, p. 350).

The research literature identifies the following predisposing factors leading to poor bereavement outcomes:

- individual characteristics of the bereaved;
- the mode of death;
- the nature of the relationship with the person who has died; and
- levels of perceived social support.

Daggett's (2002) study found that only one of eight bereaved middle-aged men showed an increased risk of morbidity. In the context of people who care for someone significant who dies from a life limiting illness, Hudson (2006, p. 695) states:

The literature shows that outcomes for bereaved family caregivers can be influenced by the duration of the illness and the various experiences surrounding the period of terminal care and the death. The overall trend suggests that a caregiver's negative perception of the patient's last weeks of life is associated with a worse outcome (Hudson 2006, p. 695).

Situational factors such as place of death have previously been considered in the research literature by Australian researchers (Goodenough et al. 2004) who studied bereavement outcomes for parents whose children died from cancer. This project focused on the place where children died, in combination with the parents' gender. The researchers concluded that fathers reported higher levels of stress, anxiety and depression than mothers when their children died in hospital rather than in the site of the home. Grande et al. (2004, p.

70) found in their study of ninety-six informal carers that a death at home was associated with better early bereavement response and better physical health six months after the death. This study claimed that there is no clear relationship between site of death and bereavement outcome, concluding that:

the association between place of death and outcome may depend on which outcomes are being measured, the basis for comparison with home care (hospice, for instance, may be viewed differently from hospital), the caregiver burden and whether home was considered the most appropriate place of death or not (Grande et al. 2004, p. 70).

Addington-Hall and Karlsen's study (1995, pp. 161-162) contradicts these findings, arguing that:

Ten months after the death, bereaved carers of cancer patients who had died at home had higher levels of psychological distress than carers of patients who died elsewhere. They were also less likely to feel that things were going reasonably well for them, that they could look forward to things or that they had come to terms with the death, and they missed the deceased more.

Hudson's study (2006, p. 700) of how well family caregivers coped after caring for a relative with advanced disease found that the majority of participants in this study were coping reasonably well two months following the death of their significant other person. This is surprising in light of the attention devoted in the research literature to the negative outcomes of bereavement (Hudson 2006, p. 700). In Hudson's study (2006, p. 700) the factors contributing to a more positive bereavement outcome were identified as:

- having the opportunity to say goodbye to the person dying;
- honouring the dying person's choice of place of death;
- being present at the time of death;
- being prepared for the death; and
- receiving support from specialist home-based palliative care professionals.

A significant finding from Hudson's study (2006, p. 699) was that information regarding final arrangements and legal and financial issues provided by workers throughout the person's dying was considered important by carers in the days following the death. Hudson (2006, p. 700) states that:

preparing caregivers with sufficient information about what to expect in the future is vitally important. Health care professionals should therefore not be unduly concerned about the potential negative impact of providing sensitive information about end of life care to caregivers. Such discussion, however, needs to be sensitively handled in accordance with the principles of therapeutic communication.

The attention devoted to the risks and outcomes of bereavement have given rise to the formulation of bereavement risk assessments. These tools are used to screen and identify people at risk of presenting with the disorder of complicated grief. Complicated grief is also referred to as absent, abnormal, acute, atypical, chronic, complicated, delayed, disorganised, dysfunctional, distorted, inhibited, intensified, morbid, maladaptive, neurotic, pathological, prolonged and unresolved grief (Kristjanson et al. 2006, p. 20). It:

involves the presentation of certain grief-related symptoms at a time beyond which is considered adaptive. These symptoms include: (a) separation distress, such as longing and searching for the deceased, loneliness, preoccupation with thoughts of the deceased; and (b) symptoms of traumatic distress, such as feelings of disbelief, mistrust, anger, shock, detachment from others and experiencing somatic symptoms of the deceased (Kristjanson et al. 2006, p. 6).

In the literature, *complicated grief* describes grief considered pathological, given that the symptoms have been:

...associated with and predictive of substantial morbidity (e.g. depression, suicidal ideation, high blood pressure), adverse health behaviours (e.g. increased smoking, alcohol consumption, poor sleep), and quality of life impairments ... what our tests demonstrate is that the set of complicated grief symptoms that we have identified, as persistent (beyond six months post-loss) and severe (marked intensity or frequency, such as several times daily) levels, are predictive of many negative outcomes and that is the basis for distinguishing them from normal grief symptoms (Prigerson & Maciejewski 2005-2006, p. 15).

Definitions, criteria and terminology associated with complicated grief are inconsistent throughout the biomedical research literature (Kristjanson et al. 2006, p. 20). The statistics also vary between studies, although it is generally accepted that between nine and twelve percent of bereaved people experience complicated grief (Kristjanson et al. 2006, p. 96). Some of the measures in complicated grief include the Texas Revised Inventory of Grief (Faschingbauer 1981); Bereavement Risk Index (Parkes 1993); Inventory of Complicated Grief, (Prigerson et al. 1995) and Hogan Grief Reaction

Checklist (Hogan, Greenfield & Schmidt 2001). These diagnostic instruments are all used to measure a person's emotional and cognitive processes in response to the experience of loss (Kristjanson et al. 2006, p. 31).

The attention given to complicated grief by researchers and clinicians over the past twenty years has been substantial. A systematic review of the literature on complicated grief was undertaken by Australian researchers who studied the research literature that was: evidence based, published in an English language, in peer-review journals between 1990 and 2005, and originating from a country with comparative health system and social and cultural similarities with Australia. The authors identified 2262 relevant abstracts (Kristjanson et al. 2006, p. 6). This figure indicates that, on average, a minimum of 150 research articles are published each year on complicated grief. Complicated grief is also proposed for inclusion in the next edition of the *Diagnostic Statistical Manual of Mental Disorders* (Kristjanson et al. 2006, p. 96), demonstrating the influence of medicine on this phenomenon. The dominant message conveyed from the field of biomedicine is that grief can be divided into the binaries of either 'healthy or pathological', 'normal or abnormal', and 'good or bad'. In this context, bereavement is perceived as a risk which warrants surveillance by health care professionals and complicated grief is a disorder which needs intervention so that people's wellbeing can be restored.

Grief and Bereavement Understood in Different Paradigms

Walter (2005-2006) proposes an alternative argument of complicated grief, not denying the existence of complicated grief but arguing that to view it as a 'psycho-pathology of the individual mourner' ignores 'its multi-faceted nature' (Walter 2005-2006, p. 77). Walter lists seven points advanced throughout the field of biomedicine and addresses each point from a social constructionist perspective. He believes that complicated grief is a:

normalising construct of psychiatric medicine; an operational requirement of bereavement agencies; a concept by which society as a whole and families can discipline mourning members; a label applied to those who actively resist cultural norms about grief; a product of a society obsessed with risk and the result of

negotiation between various parties in the bereavement field (Walter 2005-2006, p.71).

The social constructionist approach to grief offers an alternative way to understand bereavement. The social context and uniqueness of individual experience is at the forefront of this perspective, echoed by the words of Gilbert (2002, p. 223) that 'we live in stories, not statistics'. People's lives are shaped by the society in which they live. Social, historical, spiritual and cultural influences determine how individuals construct meaning of their loss. Implicit in this approach is the finding of meaning which involves three processes: sense making, benefit finding and identity change (Davis & Nolen-Hoeksema 2001; Gillies & Neimeyer 2006; Neimeyer 2006). The cultural context is critical to making meaning of loss, although those meanings ascribed to experience can change, so that what is considered a claim to truth at one particular moment can be contested or changed by the cultural context of another time:

Cultural meanings are not the same from one context to another. Neither are they stable through time. Hence, claims to universal psychological meanings (for example about the stages of grief or the tasks of mourning) should be treated as suspect for any particular person or circumstance. Living cultures are also sites of contest and debate about which meanings will be given prominence (Hedkte & Winslade 2004, p. 37).

McKissock (1999, p. 322) has applied the scientific theory of chaos to describe the process of bereavement, paying homage to the complexity and unpredictability of the experience of loss. This perspective rejects the notion that grief is staged-based and linear, with anticipated time frames to reach closure or resolution. McKissock (1999, p. 323) applies the term 'passionate sadness' to depict the intense and sometimes overwhelming sadness accompanying grief, highlighting the propensity for clinicians to misdiagnose depression in the early days of bereavement.

Silverman and Klass (1996, p. 5) highlight that it has only been within the last century that disengaging from the deceased person has become problematic and prior to this, maintaining connections with the deceased was considered a cultural norm. A person's inability or lack of desire to separate from the deceased is used as one factor for assessing complicated grief, although this line of reasoning is now being contested. Disengaging from the deceased may be more about the cultural values of modernity rather than the

lived experiences of the bereaved, who maintain the presence of the dead in everyday life through continual psychological and emotional bonds. The presence of the dead in people's lives has been challenged by the results of two empirical studies of widows, which describe the experiences of women who 'felt' they had the company of their deceased spouse (Bennett & Bennett 2000):

The view that dominates scientific discourse is that these experiences are illusory – symptoms of broken hearts and minds in chaos, or part of the futile searching for the deceased that characterises the early stages of grief. However, there is an alternative interpretational framework which allows the phenomenon to be seen as 'real' and 'natural', evidence of the possibility of continuing links with the dead beyond the grave (Bennett & Bennett 2000, p. 139).

In Bennett and Bennett's study (2000, pp. 143-144), the presence of the dead included the experiences of being observed, hearing a voice, smelling a particular odour, seeing the dead, and feeling the presence of the person in close proximity. This study also highlighted the underestimation of the length of time in which the sense of presence continues, as some of the participants in the research had been widowed for twenty years. These findings are supported by another study (Daggett 2002) undertaken with men whose wives had died within eight months to six years, which reported the theme of 'continuing encounters' (Daggett 2002, p. 631). Daggett (2002, p. 631) interprets this 'unexplainable phenomenon' as 'dreams or visual hallucinations in which the husband reunites briefly with his wife and exchanges ideas', claiming that 'the continued encounters served as adaptive responses that facilitated coping with the loss' (Daggett 2002, p. 636).

A growing number of theorists propose that it is a normal response to maintain connections with deceased persons (Attig 2004; Davies 2005; Hedtke & Winslade 2004; Klass, Silverman & Nickman 1996; Vickio 1999; Walter 1996). The findings relating to continuing bonds have achieved status in the research on grief and bereavement, challenging the dominant paradigm of 'letting go' and 'moving on'. Vickio (1999, p. 165) describes five approaches for continuing relationships with people who have died. These are:

- recognising the ways in which the deceased leave an indelible imprint upon the bereaved's lives and identities;
- striving to actively incorporate meaning and purpose from the deceased's life into the bereaved's continued living;
- embracing tangible objects or seeking out sensory experiences that symbolically link the bereaved to the deceased;
- identifying special ceremonial opportunities for including the deceased in the bereaved's lives and
- choosing to keep alive the deceased's life story.

A metaphor devised by Myerhoff (1982) and White (1989) to encapsulate the 'club of significant others in a person's life' (Hedtke & Winslade 2004, p. 7) is the theory of 're-membering' and is applied in the context of maintaining membership of deceased people. Re-membering conversations are used by narrative workers to sustain relationships with people who have died. The assumptions of being 'stuck' in grief, seeking closure and moving on by disengaging with the deceased are challenged. Instead, people are encouraged to speak about the person who has died and to explore alternative stories other than those saturated with sadness and loss.

A rites of passage model was proposed by the anthropologist van Gennep (1960, orig. pub. 1909) and further developed by Turner (1969) to explain the boundaries existing between life cycles including death. The period of liminality is regarded as one of disruption to routine and structure. Howarth (2000, p. 129) explains that liminality in this context 'describes the experience of time and place between statuses, the space between "becoming" and the rite of passage that marks it', suggesting that:

For bereaved people this liminal status may be perceived as the period between the death of their loved one and the completion of the funeral ceremony – the latter being the point at which their new status is acknowledged, for example, from husband to widower (Howarth 2000, p. 129).

Howarth (2000, p. 129) argues, however, that in late modernity boundaries between life and death are now blurred and indistinct, demonstrated by the bereaved 'keeping the dead alive' through such strategies as 'talking about the dead; anniversaries, self-help groups;

constructing biographies, commemoration and communication' (Howarth 2000, p. 131).

The dead can also play a role in 'staying alive' (Howarth 2000, p. 133):

By employing technology (the fruit of Modernity) the dead can reconstitute themselves, bringing us animated images, representations which can convey their thoughts and messages transported to a future time: a time which they will not experience.

Howarth's (2000) argument proposes that contemporary western culture is dismantling the boundary between life and death:

We may have preferences and seek to engage in particular relationships but we cannot choose with whom among the deceased we continue to communicate. The dead cannot be controlled. They continue to surprise us with their presence – suddenly brought to life on hearing a special piece of music, encountering the waft of perfume, the fleeting sight of a familiar face or expression. For the dead are mobile, resisting practices which pin them down in cemeteries or consign them to past relationships, fading photographs or lost memories (Howarth 2000, p. 135).

The 'need to develop new, complex concepts and approaches that may aid understandings of the differentiated experiences of bereaved people' is proposed by Howarth (2000, p. 136) who summarises the thesis of those seeking a theory beyond a 'medical, scientific discourse encouraging the separation of spheres' (2000, p. 135):

We are not discovering new relationships but uncovering a layer of communication which has until now been viewed as deviant or pathological and therefore hidden. The task now is not to produce a 'new model of grief'. Rather it is to amplify the whispered communication across the boundary between the living and the dead that has hitherto been muffled by the noisy, dominant discourse and prescriptive professional rituals of modernity (Howarth 2000, p. 136).

Positive Outcomes of Bereavement

Recent studies have recognised the positive changes that people experience in the wake of their loss (Calhoun & Tedeschi 2001; Edmonds & Hooker 1992; Hudson 2006).

Moody and Arcangel (2001, pp. 147-153) identify the positive outcomes, including:

- a shared sense of common humanity, including an increased sensitivity, humility and compassion for others; and

- a greater understanding of the impermanence of life and a corresponding appreciation for the importance of relationships.

Kellehear (2007a, p. 76) shares these ideas and identifies the positive aspects of grief by stating that the:

legacies of loss often increase compassion, empathy and social sensitivity; and promote the development of greater dreams, commitment and social visions for changes in personal as well as social and political life. And the dead continue to play important roles for the living as valued role models, mentors and motivators.

Tensions Operating between Theory and Practice

Currer (2001, p. 101) addresses the tensions operating between theory and practice, recognising that a sociological critique of complicated grief espouses the idea that ‘grief experts’ regulate the grieving process, but she also gives due consideration to the duty of care that practitioners have towards the people who seek support:

Whilst the sociologist can stand apart from such judgment, the practitioner cannot, although it is to be hoped that it is the service user, rather than the practitioner, who defines distress or ‘pathology’ in the context of their own life (Currer 2001, p. 101).

Prigerson and Maciejewski (2005-2006) also address the issue of duty of care, but approach the argument from a different perspective by promoting sound empirical testing and evaluation of criteria for complicated grief. Their rationale is that the people who meet the criteria for complicated grief ‘are at heightened risk of serious adverse outcomes’ (2005-2006, p. 16), declaring:

If a complicated diagnosis enables bereaved survivors and their loved ones to gain greater insight into the nature and potential source of their suffering, if it promotes the more accurate identification of bereaved persons at long-term risk of maladjustment to the loss and the development of specific treatments that target this particular form of distress, especially when treatments for depression are not especially effective in this context ... if it promotes greater sensitivity among employers to the needs of bereaved employees for time and/or assistance with adjusting to a significant loss and improves reimbursement for specific services, thereby increasing access, then it would appear that an empirically well-validated criteria set for complicated grief would proved useful to assist the significant minority of bereaved persons in need of care (Prigerson & Maciejewski 2005-2006, p. 16).

The tensions that surface between theory and practice have been addressed within the research literature (Bradey 1990; Goldsworthy 2005) with claims that the promotion of a 'theoretically expansive approach to grief and loss' (Goldsworthy 2005, p. 176) would help to recognise the inherent strengths, capacities and resilience of individuals. Bradey (1990, p. 30) asserts that pathological grief ceases to allow room for individual variation, suggesting that the behaviours which might be assessed by the clinician as measuring complicated grief may otherwise be perceived as creative coping mechanisms.

This section of the literature review has explored some of the dominant theories of grief and bereavement which encourage 'saying goodbye' and 'letting go' of people who have died whilst also highlighting the alternative approaches which cultivate and nurture connections with the deceased. It has also been highlighted how the bereavement outcomes of caregivers are considered to be influenced by factors playing a role throughout the dying and the events which transpire at the moment of death.

Concluding Comments to the Chapter

Throughout the immersion phase of this enquiry I delved deeply into the research literature to enhance my understanding of how people experience the death and final arrangements of a significant other person who died at home from a life limiting illness. Several key features emerged from this review, which support the synthesis of my research question and the methodology used for investigating this enquiry.

First, a review of the literature shows that in contemporary western society, the demographic profile of death relating to causation, age and place has changed within the last century. This change has meant that fewer people will experience the death of a significant other person until later in their life and most will delegate the management of end of life care to health care professionals in either an acute care setting, hospice or aged care facility. Furthermore, many people will engage the services of a funeral director shortly following the death of their significant other person. A consequence of these trends has meant that fewer people today are familiar with matters pertaining to the death of a close person than those in previous generations. Despite being removed from close encounters with death, many people expect that death will transpire in particular ways.

Research outcomes, however, indicate that people's aspirations are most commonly at variance with the lived experience. The principles operating in the ideology of a 'good death' promoted by the palliative care approach and the Hospice Movement imply that a 'good death' is achievable through advance care planning and the elimination of risks. The research into how and where people die in contemporary western society has revealed that each person's end of life will be shaped by a complex interplay of social, biological, cultural and political forces which impact and alter people's preferences. Second, the research from the biomedical and psychological perspectives highlights the negative aspects of care-giving and bereavement, identifying the risks and vulnerabilities of people which need to be managed by those with expert knowledge. Situated on the periphery is a small number of researchers who have recognised that positive outcomes can emerge from people's experiences of care-giving at end of life and that people are able to apply a diverse range of coping strategies to cope with the crisis of death. Additionally, there are a growing number of researchers who are approaching matters of mortality in alternative ways to traditional practice, requiring new ways of thinking and different approaches.

Third, there are few empirical studies which highlight how people attend to a death from a life limiting illness located in the site of the home and the attention given to the organisation of final arrangements. Those that have investigated this specific area have discovered that a death from a life limiting illness is a process which evolves over a period of time, and involves a range of stakeholders who have the potential to influence the course of events. Furthermore, some researchers have identified that social work is an appropriate profession to provide support throughout this period.

Finally, my research endorses the argument from Kastenbaum and Normand (1990, p. 201) that the experience of the time of death 'is a situation deserving clinical and conceptual attention'. In the aftermath of the death, final arrangements become a dominant focus in people's decision making, operating at a time marked by significant loss. The aim of this research is to understand the experience from those who have had to deal with both the death and final arrangements, thereby contributing to the experiential knowledge base for supporting people with matters pertaining to end of life. In the following chapter, I address the methodological issues which inform this enquiry.

Chapter 4: Research Methodology and Methods

Introduction to the Chapter

In this section of the immersion stage, I address the methodological issues which influence the conceptualisation of the research process and detail the research methods. The methodology informing this enquiry is embedded in the research question. Since a critical focus of my research is a deep investigation of people's experiences of attending to the death and final arrangements from the perspectives of the people who had lived the experience, I argue for adopting a qualitative approach. I am also aware that my research interest was borne from personal experience and I identify myself in the study as a 'complete member' researcher (Adler & Adler 1987, p. 67) having shared a common lived experience with the participants in the research. During my foray into qualitative research methods, I became acquainted with a model called heuristic enquiry which was developed by Moustakas (1990) which makes subjectivity and personal experience legitimate elements in the research. Heuristic enquiry is a research method, iterative, generative and reflexive by nature, which focuses exclusively on human experience. The epistemology congruent with heuristic enquiry is the social constructionist perspective which values accounts of subjective realities. Other perspectives which informed my enquiry include the strengths approach (Saleebey 1997) and an ethics of care (Tronto 1993). In this chapter, these methodological issues are discussed in relation to their relevance to the research question.

Introduction to the Research Methodology

The research methodology chosen for this study acts as a framework, directing what methods are used to obtain knowledge to inform the research question. Crotty (1998, p. 3) explains that it is 'the strategy, plan of action or design lying behind the choice and use of particular methods'. In the following section of this chapter I justify the application of a qualitative approach using an heuristic design.

Qualitative Approach

Qualitative methodologies are concerned with the construction of meanings which assist people to make sense of their experience. Denzin and Lincoln (2000, p. 3) explain that:

Qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret phenomena in terms of the meanings people bring to them.

Streubert and Carpenter (1995, p. 10) define the attributes of qualitative enquiry as:

A belief in multiple realities, a commitment to identifying an approach to understanding that will support the phenomenon studied, commitment to the participant's point of view, conduct of inquiry in a way that does not disturb the natural context of phenomena of interest, acknowledged participation of the researcher in the research and conveyance of the understanding of phenomena by reporting in a literary style rich with the participant's commentary.

Qualitative enquiry is the methodology chosen for this research because of its distinct approach to the empirical world, giving consideration to each person's frame of reference and enabling people to be studied holistically. Because I believe knowledge to be socially constructed, my positionality as the researcher and the values embedded in the research process were crucial to this study:

Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning (Denzin & Lincoln 2000, p. 8).

Positionality is closely aligned to the concept of self-reflexivity. Fook (1999, p. 12) explains that reflexivity:

is an ability to locate yourself in the picture, to understand and factor in how what you see is influenced by your own way of seeing, and how your very presence and act of research influences the situation in which you are researching.

Engaging with reflexivity facilitates the development of a 'thoughtful, conscious self-awareness' (Finlay 2002, p. 532) that avoids creating a 'concept tunnel vision' (Morse 2002, p. 1159). This process involves a deliberate scrutiny of the self in the research process, demanding a constant review of how values and beliefs shape the overall enquiry. Adler and Adler (1987, p. 69) use the term 'opportunistic complete member' researcher to describe someone whose involvement and membership with the group that is studied, precedes their decision to study the group.

Heuristic Enquiry

Previous studies using the heuristic approach have included topics of personal significance, including: childhood sexual abuse and personal reclamation (Williams 2007); breast cancer (Treulsen 2003); grief (Pilkington 1993); religion (West 1998) and counselling (Atkins & Loewenthal 2004; Marchant & Payne 2002). This approach yields an empathic ambience to personal interactions by preserving an holistic impression of people, rather than fragmented, piecemeal representations. Although the stages of heuristic enquiry imply that the research process is linear in nature, in reality the process is an iterative enterprise which offers many opportunities for reflexivity. The approach is a:

search for the discovery of meaning and essence in significant human experience. It requires a subjective process of reflecting, exploring, sifting and elucidating the nature of the phenomenon under investigation. Its ultimate purpose is to cast light on a focused problem, question or theme (Douglass & Moustakas 1985, p. 40).

Employing an heuristic methodology requires a deep and passionate exploration of the research topic. I was aware that silence and suffering were close companions of grief. I

knew that I would be sharing a place with someone where tears are cried, stories are told for the first time and silence envelops spaces where words ring hollow. I knew this would demand from me a sensitivity and a 'presencing' involving a 'tangible awareness of the privilege one has in being allowed to participate in such an experience' (Pettigrew 1990, p. 503). Conducting this research made me consider how my social, moral and political responsibilities were attached to the production of knowledge. This drove me to consider which epistemology which would inform my study. Epistemology is concerned with the study of knowledge, the acquisition of knowledge and the 'relationship between the knower (research participant) and the would-be-knower (researcher)' (Ponterotto 2005, p. 127).

Social Constructionism

Social constructionism values accounts of subjective realities. As Somerville and Bengtsson (2002, p. 121) explain:

Social constructionism, at least in its most explicit 'strong' form, assumes there is no such thing as reality in the sense meant by sociological realists and that instead, social reality is produced entirely by human discourse and interaction.

Schwandt (2003, p. 305) elaborates:

We invent concepts, models and schemes to make sense of experience, and we continually test and modify these constructions in the light of new experience. Furthermore, there is an inevitable historical and socio-cultural dimension to this construction. We do not construct our interpretations in isolation but against a backdrop of shared understanding, practices, language and so forth.

Social constructionism explains how people's stories change over time. As new information comes to light, people modify and create new accounts to incorporate into their definition of reality. Social constructionism also offers insight into how interpretations will vary between people because people are unique in their meaning making. A relativist position advocates the existence of multiple realities which are subjective in nature. These realities are constructed in the mind of the individual (Cresswell 1998, p. 76) and are 'influenced by the context of the situation, namely the

individual's experience and perceptions, the social environment and the interaction between the individual and the researcher' (Ponterotto 2005, p. 126).

People's ascription to meaning can be reshaped by their ongoing 'engagement with the realities in our world' (Crotty 1998, p. 8). In this research I am interested in the interpretations that people construct to make sense of their experience. People's interpretations change over time and different understandings can be constructed from the same experience: 'The meanings that we give to these events ... do not occur in a vacuum. There is always a context in which the stories of our lives are formed' (Morgan 2000, p. 9). Because 'our lives are multi-storied' (Morgan 2000, p. 8), it follows therefore that there is always more than one way of knowing.

Schwandt (1994, p. 129) claims that all constructions are meaningful but some are considered more meaningful than others. Intrinsic to this claim is the notion of value. People will often deem one way of knowing to be more valuable than another. The value of knowledge is dependent upon the quality and amount of available information; a person's ability to deal with the information and dominant ways of knowing (Schwandt 1995, p. 129). 'Dominant ways of knowing' is a phrase used interchangeably with the term 'dominant discourses'. These are 'embedded into our society and are often invisible until challenged by other ways of knowing' (Walter 2006, p. 15). When referring to discourses, I mean 'Structures of knowledge, claims and practices through which we understand, explain and decide things ... frameworks or grids of social organization that make some social actions possible while precluding others' (Parton, cited in Healy 2000, p. 39). The relationship between discourses and social constructionism is alluded to by Crotty (1998, p. 42) when he explains:

the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.

Discourses are always fused with power, knowledge and truth (Mills 2004, p. 16) and those discourses which have the most power, knowledge and truth have strong institutional foundations. This helps to explain why death and grief in contemporary

society are medicalised (Clark 2002; Illich 1976). Germov (1999, p. 347) explains that medicalisation is 'the process by which non-medical problems become defined and treated by medical issues, usually in terms of illnesses, disorders or syndromes'. The power, knowledge and truth of medicine and psychology influence the ways that people understand death and grief:

A prevailing assumption in western society is that people will abide by what the theories of medicine and psychology prescribe on the basis that they are the dominant discourses. To move outside of this paradigm risks the invocation of being pathologised because people step outside of what is considered to be normal (Saleebey 1997c, p. 5).

Deciding what counts as knowledge has been explored by Carper (1978). These particular ways of knowing were originally applied specifically to the domain of nursing but used in the context of this research they are helpful to make sense of all people's experiences, helping to cast light upon their behaviour. The first way of knowing is aligned with a positivist outlook, holding generalisability, cause, effect and measurement in high regard. The rest of the knowledges are allied with social constructionism, given that context, understanding and subjectivity constitute legitimate knowledge. These knowledges are identified by Carper (1978) as Aesthetic, Personal and Moral ways of knowing.

Aesthetic knowledge relies upon subjective expression and is considered to be an art. 'It is the knowing of the unique particular rather than an exemplary class' (Carper 1978, p. 16). Aesthetic knowledge does not pay heed to generalisability, measurement and the discovery of truth through cause and effect, because the knowing lies in the abstract. This type of knowing helps to explain how a person would behave differently when confronted with a similar situation. It helps to explain why someone's care for their lover dying from AIDS is very different to the care given to their elderly mother dying with dementia.

Personal knowledge is the knowing of the self and requires 'comfort with ambiguity and commitment to patience in understanding' (Streubert & Carpenter 1995, p. 4). Crucial to the concept of personal knowing is the building of relationships, placing value upon the

process as well as the outcome. The concept of presencing is important to personal knowing (Streubert & Carpenter 1995, p. 4). Presencing is concerned with being with another person in 'a way that the other person defines as meaningful' (Pettigrew 1990, p. 503). Personal knowing helps to explain how a person knows what is needed by someone who is dying despite the person dying being unable to communicate. Pettigrew (1990, p. 504) claims that 'The nature and essence of presence is such that it is understood and discerned through an intangible sense of knowing'.

The final form of knowledge espoused by Carper (1978) is moral knowing and involves knowing what is right and wrong, embodying a sense of what is fair and just. Moral knowing also involves thinking about ethical obligations in relation to others. Similar to aesthetic and personal knowing, moral knowing is 'an abstract dimension of how it is that individuals come to know a situation' (Streubert & Carpenter 1995, p. 5). An example of moral knowing is when a person who has been allocated the responsibility of enduring guardianship, decides, in the interests of an unconscious person nearing death, not to continue with medical intervention. Hudson (1997, pp. 40-41) proposes a model of professional knowledge for social work practice which incorporates the dimension of personal knowing, stating that intuition, commonsense and cultural sensibility are the three main forms (Hudson 1997, pp. 40-41). Obviously not the sole domain of social workers, these ways of knowing offer insight into all people's actions. Hudson (1997, p. 40) claims that these ways of knowing may be teased apart for the purpose of definition, but in reality they usually intersect and overlap one another.

Hudson (1997, p. 40) defines Intuitive knowledge as 'the spontaneous process of awareness that lies outside of a person's immediate consciousness and is largely based on instinct or feeling'. Commonsense is described by Gammack (cited in Hudson 1997, p. 41) as 'seeing, believing and acting according to the guidelines of socially acceptable order and reason'. The concept of commonsense is problematic because what is considered common sense to one person may not be to another. Cultural sensibilities are understood to be 'the collective meanings and shared experiences of a group of people' (Hudson 1997, p. 41). While language, values and norms may be shared within a particular group, individual members may experience an event differently:

While many aspects of this knowledge are shared, there are also aspects of this knowledge that are influenced by the individual's unique situation and perception so that it is unlikely that any two people from the same culture will view events in exactly the same ways ... shared meaning becomes interpreted and translated through individual experience (Hudson 1997, p. 41).

This perspective helps give meaning to differential grief in the one family; experiencing the same loss does not equate with individual family members sharing the same experience of grief.

Social constructionism is congruent with the qualitative and heuristic approach of this research, defining how people understand and shape their world. The next approach which has influenced this study is the strengths perspective, a philosophy and model of practice used in social work to determine what strengths and resources people have so that they can be marshalled in times of adversity (Saleebey 1997a).

Strengths Perspective

The strengths perspective is both a moral and pragmatic approach used predominantly with social work clients in case management, although the philosophy of the strengths perspective can be applied to any social work intervention. Saleebey (1997b, p. 51) defines strengths as being what people know about the world around them, ranging from those things learned intellectually or educationally to those that people have discerned and distilled through their life experiences.

Such knowledge can emerge from times of personal distress including people's experiences of grief and bereavement. In the western world, grief and bereavement are deeply rooted in a disease paradigm. The prevailing influences of medicine and psychology continue to dominate people's understandings of these experiences. To seek professional support throughout bereavement may risk a diagnosis of either absent, abnormal, acute, atypical, chronic, complicated, delayed, disorganised, dysfunctional, distorted, inhibited, intensified, morbid, maladaptive, neurotic, pathological, prolonged or unresolved grief. Knowing the authoritative and persuasive powers invested in the medical model increases the likelihood that some people who have experienced the death

of a significant other person and sought help from experts will have had their strengths and resources 'overlooked, minimised or distorted' (Saleebey 1997b, p. 51), with greater attention given to the naming of symptoms and a diagnosis of disease.

People who participate in research on death and bereavement risk a similar fate of being judged by others, particularly if they share experiences which are situated outside the variation of what is considered normal. By adopting an heuristic approach to this research topic, I recognise that people located in a medical paradigm may judge my endeavour as one of unresolved or chronic grief. My decision to adopt a strengths perspective involves recognising and celebrating people's capacities, resilience and strengths throughout their grief journey. This offsets the likelihood of purely focusing upon the myriad of alleged problems, deficits and pathologies resulting from grief. The strengths perspective does not disregard the distress and trauma operating in people's lives (Saleebey 1997b, p. 54) but deeply explores and validates experience, opting not to leave the story of survival, coping and change submerged beneath the more dominant ways of knowing grief.

Adopting a strengths perspective requires a particular way of being and interacting with people. It is founded on values of respect, trust and empathy. It demands transparency and genuineness so that relationships can develop through dialogue and collaboration (Saleebey 2007a, p. 10). It necessitates the suspension of disbelief (Saleebey 1997a, p. 11) rejecting the need to verify facts for the purpose of discovering absolute truths. The strengths approach requires from the researcher an authentic sense of curiosity, a sense of not knowing and of not assuming to know what people have experienced in their lives. It also requires a commitment to explore what is meaningful to the people who have lived the experience rather than having assumptions imposed upon them by the researcher. The strengths perspective helps to understand people in their own context. It gives voice to people who may have had their stories 'buried beneath the landslide of stereotype and ignorance' (Saleebey 1997c, p. 243).

Another perspective which has shaped this enquiry is known as an ethics of care. My role as a social worker engaged in research is predicated on an ethics of care. This approach values caring and trusting relationships. The researcher's qualities of honesty,

warmth, trust and acceptance are valued in this approach and attention is given to appreciating the uniqueness of each participant, being non-judgemental, respectful, transparent and compassionate. This theory will now be considered, showing how the ethics of care operates in the context of my research.

Ethics of Care

An ethics of care perspective is a theory and model of practice promoted by Tronto (1993) which gives primacy to the 'social basis of human life and the interdependency of human beings' (Lloyd 2004, p. 247). Tronto (1993, p. 126) describes an ethics of care as 'a practice rather than a set of rules or principles' which requires a 'general habit of mind' (1993, p. 127). Essential to this theory is the belief that care should be located at the centre of all human life (Tronto 1997, p. 101). This theory permeates my worldview. I claim that intrinsic to my research is an ethics of care because I have a moral, social and political responsibility to care for the people who participate in this research. Tronto (1993, p. 127) claims that there are four constituents of care, namely:

- caring about, noticing the need to care in the first place;
- taking care of, assuming responsibility for care;
- care-giving, the actual work of care that needs to be done; and
- care-receiving, the response of that which is cared for to the care.

The integrity of care (Tronto 1997, p. 136) is determined in the way that the four stages of care coalesce to form an integrated whole. Each of the four stages of care will be defined and their expediency to how they relate to this research process will be elucidated.

The first stage of care is known as attentiveness. Attentiveness (Tronto 1997, p. 127) means being aware of what is happening and recognising that there is a need to be addressed. Being attentive in the context of this study is noticing that personal experiences of attending a death at home and being involved in final arrangements are not commonly described in the research literature. This suggests that there may be little known about this particular time in people's lives, with a concomitant lack of knowledge

on how to support people throughout this time. The second stage is responsibility, as distinct from the concept of obligation. Progressing from the stage of attentiveness to responsibility is not a given and depends upon several factors, including a vested interest, a cultural practice or a political motivation (Tronto 1997, p. 132). The responsibility to engage in this project evolved from the knowledge gained in my personal and professional experience. Such knowledge provided me with a yearning to develop informed, context-specific support for people. The third stage is concerned with competence, involving an individual's ability to undertake a task, dependent upon skills and available resources. Tronto (1997, p. 133) states: 'Intending to provide care, even accepting responsibility for it, but then failing to provide good care, means that in the end the need for care is not met'. In this research, competence can be demonstrated through practical applications of the research, including the safe-guarding of participants' information, honouring appointments for interviews and choosing an appropriate methodology and research design. The fourth stage involves responsiveness, which is concerned with the need to start from the other person's frame of reference. Tronto (1997, p. 136) states:

Responsiveness suggests a different way to understand the needs of others rather than to put ourselves into their position. Instead, it suggests we consider the other's position as that other expresses it. Thus one is engaged from the standpoint of the other, but not simply from presuming that the other is exactly like the self.

In the context of this research, responsiveness involves participants validating their transcripts, or cross-checking in interviews for the meaning of an experience. The integrity of care is dependent upon how all these stages are negotiated. Tronto (1997, pp. 136-137) states:

Care as a practice involves more than simply good intentions. It requires a deep and thoughtful knowledge of the situation, and of all of the actors' situations, needs and competencies. To use the care ethic requires a knowledge of the context of care process. Those who engage in a care process must make judgements; judgements about needs, conflicting needs, strategies for achieving ends, the responsiveness of care-receivers and so forth.

The methodological framework acts as a reference point to which I can return anytime throughout the research process to check the trustworthiness of what is being done (Smyth 2004, p. 168). It also helps to verify the congruency between what I plan to

achieve and how I engage in the process. It directs my actions and summons me to reflect not only how I position myself in relationship to my research but also how I consider what my perspective is in relation to my claims to knowledge. Employing a moral and pragmatic approach requires consideration of the question 'How do I present myself as the author of this research and how do I represent the people who participate in this research?'. In the following section of this chapter, I detail how I represent myself and the participants in the research whilst giving thought to the concurrent issues of ownership, accountability and audience.

Representing Self

Josselson (1996, p. 61) acknowledges that while attention has often been given to the ways that researchers behave with participants throughout the interactional phase of research, less attention has been given to what is actually written. She claims that:

although we recognise that our hypotheses and conclusions about people originate in our own complex conceptual processes, we often lose sight of the additional authority our words and ideas carry when transferred to the permanence of print (Josselson 1996, p. 61).

This statement addresses issues of representation and sits at the heart of the authority invested in my research interpretation and authorship. These are issues I considered throughout the entire lifetime of this project. Using the first-person narrative in this research is a deliberate attempt to bring my role as the researcher into the text. Personal pronouns present me as a 'subjective and interactive researcher' (Ponterotto 2005, p. 132), used for the purpose of transparency, exposing my biases rather than concealing them and enabling self-reflexivity to be a legitimate part of the research process.

Representing Participants

Social constructionism espouses 'a dynamic interaction between the researcher and participant' (Ponterotto 2005, p. 131). Such an interaction requires the recall of experience through an exploration of 'intense interaction and dialogue', usually throughout a prolonged period of time (Ponterotto 2005, p. 131). An assumption existing

in the literature is that bereaved people are vulnerable (Parkes 1995, p. 172; Stroebe, Stroebe & Schut 2003, p. 236). I dispute this claim on the basis that vulnerability features in people's lives but does not totalise their being. I recognise there are sensitivities and sensibilities (Payne & Field 2004, p. 52) that I must be aware of when listening to people's stories of grief. However, if a relationship of trust is established between myself and a participant, the possibility exists for a deep exploration of experience, resulting in a disclosure of intimate details. This dialogical relationship is the first step in the process of shifting people's stories from a private space into a public arena. The knowledge generated from the disclosure of these stories puts myself, as the researcher, into a position of privilege. The matter of how I use my position of privilege and what I do with the knowledge generated from the encounters with participants is dependent upon my ways of understanding research integrity, and is associated closely with issues of accountability.

Participants' words are used to verify claims of knowledge. Dialogue risks being corrupted when taken out of context (Chesney 2001, p. 134) and the integrity of experience can be reduced when sections are fragmented from entire documents (Frank 2001, p. 356). Fine et al. (2003, p. 199) suggest reflecting upon questions when moving through the research process, such as, 'Have I connected the voices and stories of individuals back to the set of historic, structural and economic relations in which they are situated?' and 'Who am I afraid will see these analyses? Who is rendered vulnerable/responsible or exposed by these analyses? Am I willing to show him/her/they the text before publication? If not, why not? Could I publish his/her/their comments as an epilogue? What's the fear?'. These questions are intended to remind me of my accountability throughout the research process. Writing about other people's lives and distilling their experience into words means that I have a social, moral and political responsibility to exercise my authority in a way that prevents harm to participants. Chesney (2001, p. 132) emphasises this issue by stating:

The possibility of drowning out, silencing, misunderstanding or misrepresenting particular forms of knowledge creates a frightening responsibility because this knowledge comes from real people with real names, faces and lives.

A research relationship built on values of trust and reciprocity suggests that the process is one of collaboration. To a certain extent this is correct, if thought is given to how and when people participate in the research process and the guarantee that transcripts will be returned to participants for their approval. But if I decide to exercise control over the interpretive process without any contribution from participants, then I must acknowledge and claim accountability for my authorship (Chase 1996, p. 45). Representation 'does not occupy an innocent space' (Stanford 2004, p. 22) because my interpretation and the language I decide to use throughout the findings 'will be the bearers of another's experience' (Chesney 2001, p. 134).

Ownership

Closely aligned to the subject of accountability is the issue of ownership. In relation to studying other people's stories, Plummer (2001, p. 216) asks 'Who owns the life being studied?'. I believe it remains the property of the person who has shared the story, but it raises the question about what is done with the information when it 'becomes wholly cut off from the life of the teller' (Plummer 2001, p. 216). Ultimately, I am accountable for the language and concepts communicated in the research, but the stories that participants tell will always remain theirs. Before concluding this section, it is important to address the issue of audience.

Audience

My longstanding hope to make this dissertation accessible to a wide audience was tempered by reminders that this project had to ultimately serve an academic audience for the purpose of assessment. Resonating in my mind was the knowledge that the majority of people who participated in the research voiced their interest in reading either the findings of the study or a full copy of the thesis at the completion of the research. Some of the language in this study is not everyday vernacular because it is situated in a scholarly context, but the experiences and voices of the participants have stayed with me throughout the writing of this project and I am hopeful that I have remained 'faithful to forms of knowledge gained in personal and intimate settings' (Chesney 2001, p. 132).

The next section of the immersion stage attends to the methods used to address the research question, ‘What are people’s experiences of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness?’.

Introduction to the Research Methods

In this study, the term *method* is used interchangeably with the terms *practices* and *techniques* (Walter 2006, p. 377). By describing the method used, I aim to achieve transparency in the research process and expose for public scrutiny my conduct as the researcher (Anfara, Brown & Mangione 2002, p. 29). The methods in this study reflect the philosophical assumptions embedded in the research (Roberts & Taylor 1998, p. 170). I also recognise that they are considered appropriate for studying the ‘sensitive topic’ (Liamputtong & Ezzy 2005, p. 205; Stroebe, Stroebe & Schut 2003, p. 238) of grief and bereavement (Carverhill 2002, p. 198; Dyregrov 2004, p. 397; Rolls & Relf 2006, p. 288) and I regard them as reliable in eliciting information and creating meaning of human experience.

The remainder of this section is divided into four parts. First, I detail how I accessed and negotiated entry into the lives of research participants through the practices of procedural ethics and recruitment strategies. In the second part I discuss how information was gathered and assembled throughout the practices of administration, interviews, memos, journal entries, transcription, telephone conversations and personal correspondence. I also identify how serendipitous and unanticipated outcomes emerged in the research process from these practices. In the third section, I attend to how meaning is made from the information gathered in the study by means of conducting a thematic analysis. The final section addresses the dissemination of research findings and focuses on the sharing of information with a wide audience.

Negotiating and Accessing Entry into the Lives of Research Participants

Negotiating my way into 'the field' began with the design, presentation and submission of my research proposal to the Research Higher Degrees Unit and to the School of Sociology and Social Work at the University of Tasmania. Approval to commence the project was received in the latter part of 2004. Having permission to embark upon the project enabled me to submit a 'Social science application for research involving human subjects' to the University of Tasmania Human Research Ethics Committee in October 2004, and approval to 'enter the field' was received within two months.

Procedural Ethics

Included in my ethics application was a statement justifying the research on the basis that it would contribute to the knowledge of allied health care workers supporting people dealing with end of life matters. The ethical principles addressed in the application centred round the four main issues of informed consent, confidentiality, anonymity and protection from harm. These issues are explained below.

Informed Consent

The principle of informed consent is embodied in the act of ensuring that participants are aware of what their participation in the research entails, and that they have agreed voluntarily to participate without any pressure from manipulative or coercive influences (Israel & Hay 2006, p. 61). Abiding by this principle meant that I endeavoured to be transparent in my research practice. Achieving this goal involved the following methods. I spoke with each person who voiced an interest in the study, introducing myself and my role in the project. I invited people to ask any questions relating to the study and offered to supply an information package containing printed details of the project. People who were interested in participating were asked to provide their contact details for the purpose of forwarding an information package. Included in this package was a cover letter (see

Appendix 1), an information document (see Appendix 2), examples of interview questions (see Appendix 3) to be asked in a face-to-face interview and a statement of informed consent (see Appendix 4). In the cover letter I positioned myself as a 'complete member' researcher (Adler & Adler 1987), disclosing that I had attended to the death of, and been involved in the final arrangements for, my mother who had died at home from a life limiting illness. I chose to hand-write my signature on all cover letters and information sheets.

I also asked for a contact number and arranged a mutually agreeable time within the week to telephone so that I could determine people's ongoing interest in the study. These details were entered onto a computer spreadsheet. I explained that there was no pressure to continue if people decided against future involvement with the project. People were also advised that they could withdraw consent from the study at any time or make contact with me by telephone if any queries arose about the project. To mitigate the risk of manipulation or coercion I decided not to recruit bereavement clients from the palliative care service where I worked.

Confidentiality

The principle of confidentiality is concerned with ensuring that the information obtained from participants is kept private and 'used only by the researcher and only in particular ways' (Israel & Hay 2006, p. 77). The precautions I put into practice to maintain information in confidence involved using only myself in the research process to contact participants and manage all research information, including the interviewing, recording, transcribing and analysis of information. Information obtained from participants was kept in a locked filing cabinet and electronic data files were maintained on a computer protected by password entry. Closely aligned with the principle of confidentiality by virtue of its relationship with the notion of privacy, is the principle of anonymity.

Anonymity

Anonymity 'refers to the protection of respondents from identification as participants in the research' (Habibis 2006, p. 67). Procedures employed to avoid the identification of individuals included: omitting names, using limited demographic details, and providing participants with the opportunity to edit their own transcripts. The assumption that anonymity is a staple tenet of social research was challenged by three participants who expressed their lack of concern with this principle. These people explained that they felt they had nothing to hide and the allocation of real names helped to honour the life of the person who had died. Grinyer (2002) contests the assumption that anonymity is an orthodox feature of grief and bereavement research, claiming that participants may wish to be acknowledged because it enables them to keep ownership of their stories. However, the request to retain real names in the research was in stark contrast to the needs of four other participants whose involvement with the research depended upon strict adherence to the principles of anonymity and confidentiality. These participants did not want significant other people in their lives to know about their involvement in the research. In the need to protect these people's anonymity and confidentiality, I curtailed mailing research information, made contact by mobile phone, and was amenable to being available for interviews at any time in a range of settings.

Following the interview process, one participant telephoned to request no further contact with the project and declined the offer of a copy of the transcript. In response to the request to withdraw from the project, I offered to make the transcript available to read in a safe and confidential location; however, this offer was also declined. This participant shared my aspiration that the project would help other people in the community and expressed gratitude for being involved.

After reflecting upon the need to be respectful of these various requests, I decided to apply a code number to each person. My decision was made on the basis that featuring in participants' stories were other people's details. Tasmania is a small state and has a relatively small population, making it possible that people featuring in participants' stories could be identified. It became necessary therefore to protect other people's rights to privacy. I decided to allocate a code number to each participant which corresponded

to the order in which people's interviews were transcribed. One person chose to donate a copy of a manuscript rather than being interviewed and I also allocated this document a number. Each number is printed on the cover page of each person's transcript and is found in the bottom righthand corner of participants' quotations in the findings.

Protection from Harm

The last ethical principle to be described is that of protection from harm, also known as the principle of non-maleficence. This principle concerns the minimisation of risks of harm or discomfort to participants (Israel & Hay 2006, p. 95). Given the sensitive nature of the research and the need to recall past experiences, I recognised that there was the potential to evoke strong emotions and vivid memories. The following procedures were applied to address the risk of emotional harm: all participants would be voluntary; participants would be informed of the risk of emotional stress; participants would have experienced the death of a significant other person more than ten months ago; participants would be provided with contact details to support services if they sought debriefing or support post-contact; and if participants became upset throughout the interview they would be offered the opportunity to stop and decide whether or not they wanted to continue. My role as a social worker employed in palliative care offering bereavement support meant that I regularly worked with people who expressed their grief and I was confident that I had the skills and sensitivity to interview people with care and compassion.

Once ethical issues had been attended to, negotiating entry into the lives of research participants began with approval to embark upon the project from the University of Tasmania Human Research Ethics Committee and the School of Sociology and Social Work.

In the next section of accessing and negotiating entry into the lives of research participants, I describe the selection criteria to be a participant and the strategies employed to recruit participants.

Selection Criteria for Eligibility as a Research Participant

People who met the following criteria were invited to make contact with me for further details concerning participation in the research:

- lived in Tasmania at the time of being interviewed;
- could speak English;
- was aged eighteen years or more;
- had looked after someone significant at home throughout the course of a life limiting illness;
- had attended to the person's death in the site of the home;
- had experienced the death of the person more than ten months ago.

The criterion to speak English was imposed by resource constraints. No funds were available for interpreters or transcribers. Advertising for the recruitment of participants was executed in English and it is acknowledged that this limitation may have excluded potential research participants from culturally and linguistically diverse backgrounds. The rationale for not interviewing participants until ten months following the death of their significant other person was based on my intent to minimise the risk of interfering with people's grief throughout their early bereavement. Stroebe, Stroebe and Schut (2003, p. 239) posit the ethical question 'how soon?' following a death can a researcher expect someone to participate in research, and conclude that there is no simple answer. My study was not seeking facts to verify people's experience. Rather, this study aims to explore people's constructed realities from which the passing of time could offer broader and deeper meanings. Consequently, there was no period considered too long following a death since the making of meanings can continue for a person's lifetime. The next section of the research methods addresses the recruitment of participants and highlights the inherent challenges involved in engaging particular recruitment strategies.

Recruitment of Participants

Two stages of recruitment are discernible in the research process. Triangulated sampling was used through purposive, snowballing and opportunistic sampling strategies (Patton 1990, p. 169). In the first stage, small posters advertising the project were distributed throughout several public places including a university campus, three community health centres and a school staffroom. Contact was made with other social workers employed in the community, one of whom was involved in a bereavement support group and several who were employed in palliative care. I spoke about my research at social gatherings and I presented at four different forums, two being for academics and two for professionals working in end of life care.

In the second stage of recruitment, eighteen people became research participants, primarily through the means of a volunteer sampling strategy (Patton 1990, p. 169). Contact was made with a journalist from the local newspaper and I provided verbal and written details of the project. An article subsequently appeared in a weekend edition of the *Examiner* newspaper featuring a photograph of myself, details of the project and how I could be contacted if people wanted more information. In response to the newspaper article, I was invited for an on-air interview by a radio presenter from the Australian Broadcasting Commission. The following notes were recorded in my journal demonstrating how unexpected outcomes emerged from engaging the assistance of the media:

Monday 30th January 2006. I was finally interviewed today by a journalist from the Examiner newspaper. I found the experience enlightening because I was audio taped and so I got a sense of what it's like for the research participants who are interviewed by me. I felt really uncomfortable because I wanted to deliberate over every word knowing that my words would be fixed in print for ever. I wonder how it will be reported because I have no authority over how I will be ultimately represented. At the same time I get a sense of my positionality in the research.

Sunday 19th February 2006. Article was printed in the Examiner today almost three weeks following the interview. In light of taking almost three weeks to be interviewed, the process of using the media for recruitment purposes has taken longer than I anticipated.

Monday 20th February 2006. Received eight phone calls today in response to the newspaper article and one person requested an information package for a friend.

Tuesday 21st February 2006. Two more people interested in being interviewed. I was also contacted by a radio presenter from the Australian Broadcasting Commission in response to the Examiner article wanting to do a voice recording for the Drive show. Was interviewed over the phone at 2.30pm and went to air before 5.00. Two more people contacted me by telephone immediately after the interview went to air.

Wednesday 22nd February 2006. Three more people contacted today who are interested in participating in the project. One man contacted whose wife had died less than a month ago. I thanked him for his interest in the project and explained that the journalist from the newspaper had chosen not to include all the selection criteria in the newspaper article, stating that what had been omitted from the article was that participants needed to have experienced the death of someone more than ten months ago. He believed that I should interview people as soon as possible after the death because the details of the death are still fresh in people's minds. I explained how my research did not want to interfere with people's grief journeys so early in their bereavement and that I was bound to abide by these criteria by virtue of my ethics application. I also explained how I was more interested in the meanings that people made from the experience rather than factual information. He asked me to contact a health care professional who could testify that his story was valuable for this study. I thanked him again for his interest and arranged to telephone him again later in the week.

Thursday 23rd February 2006. I've now realised how employing the media's assistance can have unanticipated outcomes for the research process. Four more people made contact today about the research. One person's mother had died less than a fortnight ago. I spent about ¾'s of an hour speaking to this woman about her grief journey and she said that whilst they cared for her mother and were with her when she died, her mother relocated from home into a hospital for her final two weeks of life. I explained the selection criteria for the study and we continued to chat about her experience and the effects of her grief. A very poignant story – she shared with me some of the intimate things she did when her mother died, including cutting off a lock of her mother's hair. She also told me that she feels stronger than she had anticipated, but has had people making judgemental comments about her decision. In supervision today, I spoke about my concern for the people who had made contact with me who were not eligible for inclusion in the project. I decided to offer the people who met the research criteria but had experienced the death less than ten months ago the opportunity to record their story in nine months' time, giving them the opportunity to contact me again if they were still interested in participating in the research. I also believe it's important to provide details of community support to these people

My attempt to telephone the person whom I had arranged to contact again was unsuccessful so I decided to use personal correspondence as a means of communication. I was already aware that this person knew of available bereavement supports in the

community. After forwarding the following letter, I did not hear from this person again. Following is a copy of the letter.

Dear [name]

Thank you for leaving a message on my office phone. I appreciated you providing your address details and your willingness to speak with me. Due to the limitations of my study I'm unable to offer you a formal interview on the basis that your wife died less than ten months ago. The reasoning underpinning this criterion is to mitigate the possibility of participants experiencing any harm in the early stages of their grief journey.

Whilst I cannot formally interview you I can offer you one of two options. I'm able to phone you and you can relate your experience to me without it being recorded, or you can contact me in nine months and I can interview you. I know you feel it's important to share your story with me now so that as time elapses, your memory of your experience does not fade. I will respect whatever decision you make. I also understand if you change your mind and decide not to participate. I wish you all the very best.

With kind regards

Marg

Initially I decided to limit my study to twenty participants, believing that this number was realistic in terms of the resources available to me. A number of people contacted me explaining that they had deliberated for some time whether or not to participate, finally deciding to take a chance and share their story. These people were accepted into the study. With twenty-eight people willing to be participants, I commenced gathering and organising the research data.

Gathering the Research Information

The following section addresses the gathering and organising of the research information through the practices of administration, interviewing, memo writing, journaling, transcribing, telephone conversations and personal correspondence.

Administration

Arranging interviews and equipment in preparation to 'entering the field' necessitated effective organisation skills not simply for the purpose of being methodical but to ensure the integrity of the research process. For matters relating to participants' personal details I designed a spreadsheet to record names, addresses, telephone details, dates when information packages were sent, dates arranged to telephone people to determine their interest in participating, dates and times arranged for interviews, places of interview, and dates when transcripts were sent to participants. I also recorded idiosyncratic details such as 'Do not send correspondence'. This document was essential to manage this data and to organise my interview timetable. People occasionally needed to reschedule their interview appointments and this document enabled me to reorganise dates or interview sites with a minimum of fuss. It was also beneficial when people moved house or changed their contact details.

I maintained an Excel spreadsheet to record the kilometres I travelled. I purchased an iPod for recording interviews, an atlas of Tasmanian towns, several boxes of tissues, several exercise books and photocopied extra information sheets and statements of informed consent forms in case people mislaid their copies. I recorded a voice message on the telephone in my university office inviting people to leave a message when I was unavailable to answer the telephone which explained that I would make contact when I returned to my office.

Interviews and Journaling

Interviews were chosen as the primary research method given that their purpose is to shed light on other people's meaning making. Researchers studying grief and bereavement (Donnelly, Michael & Donnelly 2006; Dyregrov 2004; Rolls & Relf 2006; Steiner 2006; Winston 2006) have used interviews to obtain 'deep information and knowledge' (Johnson 2001, p. 104) from participants, with the intent to derive meaning from their experiences. Interviews are often linked to the practice of conversation (Denzin & Lincoln 1994; Marshall & Rossman 2006; Rice & Ezzy 1999) and are valued in heuristic enquiry:

The conversational interview or dialogue is most clearly consistent with the rhythm and flow of heuristic exploration and search for meaning. Dialogue is the preferred approach in that it aims towards encouraging expression, elucidation and disclosure of the experience being investigated ... dialogue involves cooperative sharing in which co-researchers and primary researchers open pathways to each other for explicating the phenomenon being investigated. This means receiving the other as a partner, accepting and affirming the other person (Moustakas 1990, p. 47).

I conducted a pilot interview, the purpose of which was to check the quality of the recorded information and to determine if modifications were needed. Feedback was sought from the participant concerning the types of questions asked and the manner in which I conducted the interview. The interview schedule was structured around three stages of experience: pre-death, death and post-death. Depending upon the content and nature of the interview, the words in the questions would vary, but in all instances the three stages were addressed. In the first stage the question, 'What was your relationship with the person who died?', was presented. This stage of the interview aimed to bring the person who had died into the dialogue for the purpose of developing a context around the experience of death. The interview schedule progressed towards the moment of death and a question was asked with reference to what happened at the time of death. The last stage of experience, post-death, involved a question, 'What happened after [name] died?'

My primary method of generating information was influenced by the collaborative communicative process of 'reflexive dyadic interviewing' (Ellis & Berger 2002, pp. 853-854). This is a research method employed by auto-ethnographers for the purpose of self-conscious reflection. These interviews are similar to conversations whereby participants are welcome to ask questions of the researcher and the researcher is given space to share stories in the context of a developing relationship (Ellis 1998, p. 51):

The researcher's disclosures are more than tactics to encourage the respondent to open up; rather, the researcher often feels a reciprocal desire to disclose, given the intimacy of the details being shared by the interviewee (Ellis & Berger 2002, p. 854.)

Active listening skills were also used involving minimal encouragers, maintaining eye contact, keeping an open posture and employing appropriate silence. I was mindful that

my witnessing of another's experience not only demanded good listening skills but also an awareness of how my presence could impact upon another person's state of being. I understood that the way I listened to people's stories had a direct bearing on how people spoke to me, and this in turn had a bearing on what I could learn from people. In heuristic interviewing, the data generated is dependent upon accurate, empathic listening, being open to oneself and to the participant, being flexible and free to vary procedures in order to respond to what is required in the flow of dialogue, and being skilful in creating a climate that encourages the participant to respond comfortably, accurately, comprehensively and honestly in elucidating the phenomenon (Moustakas 1990, p. 48).

People were offered the choice of where and when they wanted to be interviewed. Three people opted to be interviewed in an office at the University, one person was interviewed in my home and the rest chose to be interviewed in their own homes. One person preferred not be interviewed, deciding instead to forward a copy of the manuscript she wrote after her son had died. Although I had said that interviews would take between one and two hours, I did not apply a time limit. Interviews ranged in duration from three-quarters of an hour to three-and-a-half hours, although time spent with participants usually exceeded interview time. Occasionally people would offer me something to eat or drink before the interview began, thereby taking the initiative to build a relationship of rapport. Before the interview began I would reiterate the risks of being involved in the research, although Rosenblatt (1995, p. 148) cautions that 'qualitative interviews have an unpredictable, unfolding quality that makes it impossible to warn people of everything that will occur during them'. Rosenblatt recommends a 'processual consent' technique which transpires throughout the research interview, using questions like, 'Are you feeling okay with this interview? Are you alright to continue?'.

All interviews were recorded using an iPod. I provided an explanation of how the iPod worked and stated that I was happy to turn it off at any time that participants wanted the recording to cease. Warren (2002, p. 92) highlights the propensity for people to speak about their experiences either before or after an interview has finished. This occurred many times while I was with participants and I would ask if people minded whether I recorded on paper what they had said. Memos became a staple means of recording information throughout the study. During their interviews some people used artifacts

which served not only to 'braid the posthumous with the living' (Hedkte & Winslade 2004, p. 86) but acted as triggers for people's memories (Clandinin & Connelly 1998, p. 165). Diaries, photographs, jewellery, letters, poems, order of funeral service sheets and other precious memorabilia helped people to recall past events and personal experiences in addition to making meaning of their experience. I understood that these were privileged moments for me to share with people that were not captured on the recording:

To supplement the interview data, the heuristic researcher may also collect personal documents. Diaries, journals, logs, poetry and art work offer additional meaning and depth and supplement depictions of the experience obtained from observations and interviews (Moustakas 1990, p. 49).

Journaling was used in combination with interviews to record my ideas, reflections, emotions and questions as well as providing an outlet for responding to the act of research. Keeping a journal enhanced critical reflective practice, assisted with recalling events and experiences, and was used as a strategy for self-care. I had underestimated the emotional impact upon myself doing research on people's experiences of death and final arrangements. I believed that the skills I had developed as a palliative care social worker would hold me in good stead; however, I gradually began to realise that the act of research was quite different from the work I managed in palliative care. Immersing myself in people's stories again and again meant that I needed to have a strategy for self-care to prevent compassion fatigue (Figley 1996). Keeping a journal, interviewing a maximum of two people per day, having supervision and doing regular exercise were all practices that I undertook to maintain my wellbeing. Occasionally walking away from the research was also used as a strategy for self-care as explained further in stage 3 of this study.

The personal, sad and intimate nature of people's stories often meant that they would cry during their interviews. Prior to the interview commencing, I would explain that I was comfortable with sadness and it was possible that I would cry as well, although my focus would always remain with the participant and on their well-being. Parkes (1995, p. 175) and Rosenblatt (1995, p. 144) both state that interviews have a therapeutic value and regard the expression of grief to be normal throughout studies of bereavement, but add that there must be established guidelines for conducting ethical bereavement research to

avoid the risk of harm. I recognised the potential harm that could be generated from conducting a deep exploration of people's experiences of end-of-life and bereavement, and considered the ethical challenges raised by this project. I recognised that I would be asking people to recall memories which were private, some of which had never before been shared and I also knew that I was asking people to return to a time which some would describe as 'terrible'. I knew from practice wisdom that a consequence of recalling these experiences can impact upon people for days afterwards, so I always checked how people were at the end of their interviews and usually waited for a period of time before I departed to ensure that people were feeling comfortable to be alone. I would offer to phone people who became distressed in the following days to see how they were faring, although all participants declined this offer. Satisfied that I could meet all the ethical criteria proposed by Parkes (1995, pp. 178-181) in a checklist he considered all bereavement research should meet, I embarked upon this project knowing that I was entering very private spaces of people's lives, discussed further in the Incubation stage of this thesis.

In the next section I describe the 'logistical and interpretative challenges' (Poland 2002, p. 632) which emerged in this study through the practice of transcribing.

Transcribing

Moustakas (1990, p. 49) explains that:

The interview should be tape-recorded and later transcribed. The basic data for illuminating the question and providing a basis for analysis of constituents, themes and essences of the experience come from transcriptions and notes taken immediately following the interview.

Transcribing is a labour-intensive and time-consuming research practice. I discovered that fifteen minutes of interview recording translated into approximately one hour's transcribing. I transcribed all interviews in their entire recorded format and made notes throughout the process. Each transcript had a cover page and I waited at the University printer whilst each document was bound. I believed that it was important to give back to

participants a well-presented and durable document. Fatigue and sound interference on recordings had the potential to affect transcription quality so it was important to ask participants to check their transcripts for the purpose of verifying the accuracy of their interview transformed into text. Participants' transcripts were either posted or hand-delivered with a cover letter. A copy of the cover letter follows.

Hello [name],

Here is your transcript from the interview I recorded with you in [month]. Thank you for your willingness to share your story with me. I am mindful that sharing some of the events can be upsetting and I hope that this transcript will not cause you any further grief.

If you intend to read it I suggest you find a quiet space free from any demands. The words printed on paper can have an energy quite different to the words we speak and some people have said to me that they have been quite emotional reading their own lived experience. Please know that there is no pressure from me that it has to be read.

You may notice that I have not recorded your name nor the names of other people that you mentioned in your story. Instead, I have used a letter or space to denote their inclusion. I have also done this when you have indicated a location. I hope that this does not in any way minimise your experience; my aim in doing so was to protect your anonymity and the anonymity of other people involved with your story.

If you want to discuss the transcript with me please do not hesitate to contact me on 63 243657. I'm hoping that all transcripts will be completed by the end of July 2006. Throughout the year, I plan to analyse all the material I have collected and to write my thesis. I aim to submit my thesis in 2007.

I hope you are well and I wish you all the very best for the year ahead.

With kind regards,

Marg Hughes

Transcribing presented a number of challenges which I had not anticipated, including how people would be affected by seeing their speech translated into prose because 'the concept of "sentence" does not translate well into oral tradition or vice versa' (Poland 2002, p. 632). I had made the grand claim that I would transcribe the iPod recordings verbatim but throughout the practice of transcribing I came to realise that I had to make

some editing decisions. Occasionally sentences would continue for what seemed to be a very long time or switch to other ideas without an end to the previous idea, appearing much like streams of consciousness. Concomitantly people would use sounds of 'um' or 'ah' or 'mmn' during moments of hesitation in their speech which gives prose the impression of being disjointed.

After reading their transcripts, five participants voiced disappointment in themselves for using what they considered to be a plethora of ums, ahs and mmns, claiming that their transcripts appeared at times incoherent. I communicated with the five participants and normalised this phenomenon, stating that in terms of articulation their transcripts were no different from any others. Poland (2002, p. 633) states that, 'Verbal interactions follow a logic that is different from that for written prose and therefore tend to look remarkably disjointed, inarticulate and even incoherent when committed to the printed page'. Reflecting on participants' discomfort in seeing their speech transformed into prose lead me to consider the ethical implications of transcribing. Poland (2002, p. 634) highlights the ethical dimension of transcriptions and endorses, when publishing the results of the study, 'a little skilful editing, without substantially altering the gist of what was said'. He believes that this should occur only after the analysis occurs.

Another transcribing issue that surfaced was in response to my assurance that I would remove any information that participants wanted omitted from their transcripts. Four participants wanted to extract certain information from their transcripts. I honoured their request for self-censorship but I was surprised how this stirred a response of loss within me. I had envisaged that I would fulfil my guarantee without any further thought, but this was not the case. I was disappointed in myself that I had experienced this feeling but editorial decisions provided an opportunity for me to reflect upon the social and political responsibilities I have towards the people who offered their experiences for this study.

Telephone Contact

In response to participants receiving their transcripts three people made contact with me by telephone to add information to their stories. I asked permission from these people to

take notes while we were talking and thanked them for their interest in the study. These participants explained that the interviews had offered another opportunity for them to revisit their experience. Being interviewed, and later reading their own transcript, provided new insights or reminded them of something significant in their story, adding meaning to their experience.

Personal Correspondence

As I had underestimated the time that it would take to transcribe the interviews I decided to write to the participants to provide an update on my research schedule. The next section illustrates how the writing of letters developed a strong and pervasive presence in the research. The following letter was used to communicate information to participants in the initial phase of the study.

Dear [name],

I hope you don't mind that I keep in touch, but I thought I would let you know what's happening at this stage of my research. This letter will be sent to all participants who are willing to receive correspondence from me. I thought that it's been some time since I had contact with everyone and people may be wondering what's happened in the interim.

I began interviewing in August and I finished meeting people who had offered to share their stories in early April. The interviewing phase has taken me a little longer than I anticipated, but I realise that undertaking a PhD is learning about things that I didn't already know! So, I now know that sometimes time frames can take longer than anticipated.

Twenty-eight people participated from all over Tasmania. Three of the twenty-eight participants were men. People identified themselves in their stories as the wife (11); husband (2); sister (1); daughter (8); mother (4); father (1) or family friend (1) of the person who had died. I managed to clock up more than 2850 kilometres driving back and forth in my car. I remember I'd often set off to meet someone, driving with music blaring from my CD player only to return home at the end of an interview stunned into silence. Such was the impact of the stories I heard; even the stories that were shared by people who said (and there were many) that they could not imagine that their story could be of any significance to my study. Every story shared has offered me another perspective that allows a greater understanding of how other people live. I am very grateful to everyone who communicated their precious memories and insights from a time which marked great sadness and loss.

Stories and insights were shared in various ways. I met most people in their own home and recorded their story on my iPod, although a few people preferred to come to the University. One mother donated her manuscript which was a moving account of how she and other members of her family experienced her son's end of life. Some people have contacted me after their interview either by phone or via correspondence to offer further insights. I know that I have previously used the term 'generosity of spirit' when I refer to people's contributions, but for me that has been an overwhelming outcome from this study.

To date I have transcribed ten interviews. I'm hoping that everyone will have their transcript returned by the end of June. Once again, this is taking a little longer than I expected. Once I have transcribed everyone's stories, my task is to do an analysis, and I suppose come up with one story from many stories! I have to say the task is a little daunting but already I know that some common themes are woven between many of the stories. I also know that there are some unique differences too.

If you would like to read a copy of my thesis when it is finished, or alternatively read the findings chapter, please do not hesitate to let me know and I will make it available to you. I anticipate (though I now say this tentatively with some practice wisdom) that I will complete my thesis in the latter part of 2007. I have included a copy of the article from the Sunday Examiner, which I know some of you did not see. For others, I realise that this was the means by which you learnt of my research. I have found the undertaking of this research enormously rewarding and a very great privilege to have met every participant.

Wishing you blue skies ahead.

With fond regards

Marg Hughes

PhD Candidate, University of Tasmania

Personal correspondence became a serendipitous development in this study that I had not anticipated. I received twenty-four letters from eight participants over the course of this study. The letters started arriving either after I sent people their individual transcripts from their interviews or in response to a letter that I forwarded to provide an update on the progression of my research schedule. I would feel a mix of anxiety and excitement when I found a letter addressed to me in the postgraduate mail box. Sometimes cards, poems and other pieces of memorabilia would be enclosed. I received notes of gratitude and well wishes encouraging me to continue with my study. Occasionally people would reflect upon the process, explaining how the interview had evoked strong memories,

sometimes painful, sometimes comforting – sometimes people mentioned the therapeutic aspect of participating. People added insights to their experiences and ascribed meanings to some past events. More often than I am proud to admit they would identify where I had made spelling errors or other mistakes in their transcripts. I always replied to the people who sent me letters and I would correct those transcripts with mistakes, sending back a revised, bound copy. Personal correspondence eventually became a vehicle to continue relationships with participants by exchanging ideas, feelings, thoughts and reflections.

Letter writing presented me with an ethical dilemma. I had not anticipated personal correspondence being used as method in the project nor did I expect it to emerge as a propitious means to continue relationships with people who participated in the research. Although some of the participants intended for their letters to be used to add information to the research, many were written with an intimate tone to the text not intended for the public's gaze. To ask if I could use extracts from these letters for the findings of the thesis seemed disrespectful. For this reason, those letters were not used to generate information for this project.

The third part of this section addresses how the information collected during the project was analysed by 'recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work' (van Manen 2001, p. 78).

Thematic Analysis

Moustakas (1990, p. 43) claims in respect to heuristic enquiry that 'after the data are collected they must be organized and presented in a way that depicts and illustrates the themes, meanings and essences of the experiences that have been investigated'. This study applied a thematic analysis to the interviews, journal notes, personal correspondence, transcriptions, memos and telephone conversations for the purpose of making sense or giving meaning to participants' experiences (Luborsky 1994, p. 190; van Manen 2001, p. 87). A thematic analysis enables 'direct representation of an individual's

own point of view and descriptions of experiences, beliefs and perceptions’, thereby giving weight to the voices and experiences of participants’ (Luborsky 1994, p. 190).

People enquired what I intended to do with their transcripts. I explained that I planned to do a thematic analysis which involved searching for meanings in their stories. The notion of theme was familiar to participants, thereby serving to demystify the research process. I found that people accepted the utility of a thematic analysis as a legitimate method to find meaning from their interviews. Luborsky (1994, p. 192) supports my finding, claiming that ‘the concept and appeal of themes is rooted in widely shared socio-cultural settings and not strictly limited to a rarefied objective scientific context’. For the purpose of this study I adopted the definition of theme from DeSantis and Ugarriza (2000, p. 362) who claim that a theme is ‘an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole’. Van Manen (2001, p. 88) claims that a theme ‘is the means to get at the notion’ but cannot ‘unlock the deep meaning, the full mystery, the enigmatic aspects of the experiential meaning of a notion’. Themes are therefore reductions (van Manen 2001, p. 88) or condensed meanings (Luborsky 1994, p. 206) of notions which ‘unite a large body of data that may otherwise appear disparate and unrelated’ (DeSantis & Ugarriza 2000, p. 355). My thematic analysis does not intend to appropriate or improve upon the original expression of people’s experiences.

Braun and Clarke (2006, p. 82) posit that ‘the keyness of a theme is not necessarily dependent upon quantifiable measures – but rather on whether it captures something important in relation to the overall research question’. The notion of *prevalence* has been used (Braun & Clarke 2006, p. 82) to judge the merit of applying a theme to a study by means of identifying repetition or central meanings (Luborsky 1994, p. 206) in people’s experiences. I use the term *conspicuous* to denote the specific items in the research data which grab my attention, and I apply the processes of frequency, omission and declaration identified by LeCompte (2000, p. 148) to find these items in the data. *Frequency* refers to an item being recurrent in the data, appearing numerous times within one transcript or materialising in many transcripts. *Omission* refers to those items which are conspicuous by their absence. As LeCompte (2000, p. 148) explains: ‘Items

sometimes can be identified because they never appear even though researchers might think it reasonable that they would' and *declaration* refers to the process of participants identifying and informing the researcher that items exist. The actual process of transforming the data into research results (LeCompte 2006, p. 146) was not a linear process: 'it is a more recursive process where movement is back and forth as needed' (Braun & Clarke 2006, p. 86). The practices employed in achieving a thematic analysis for this study involved the following steps:

- **Actively Listening for, and Making Notes about Commonalities, Differences and Patterns during and after Interviews**

The thematic analysis commenced within the interview during the immersion phase of the enquiry. Luborsky (1994, p. 202) recommends that the researcher attend closely to participants' stories so that those items considered conspicuous can be identified and examined with the participant: 'Items are the specific things in the data set that researchers code, count and assemble into research results' (LeCompte 2000, p. 148). Listening to the recorded interviews after being with each participant offered an opportunity to re-examine the dialogue and search for conspicuous moments in the interview.

- **Transcribing**

Transcribing is more 'than simply a mechanical act of putting spoken sounds on paper' (Braun & Clarke 2006, p. 88); it offers the opportunity to become re-acquainted with the content of interviews thereby developing 'a far more thorough understanding' (Braun & Clarke 2006, p. 88) of people's experiences. This period of preliminary analysis offers an opportunity to 'tidy up' (LeCompte 2006, p. 148) the vast corps of data, organising and sorting it into a manageable and retrievable collection. The process of transcribing the notes I made formed the basis of my participant profile summary.

- **Creating a Participant Profile Summary**

The ‘participant profile summary’ enabled me to start organising and analysing the information I had collected after each interview. The following table illustrates the summary I devised, although details have been altered to avoid participant identification.

Table 1: Participant Profile Summary

~ Participant	Deceased	Disease	Supports	Comments
Mother Esther	Daughter	CA breast Surgery Chemotherapy Pain and symptom management	Doctor Palliative Care Team Family	Died in mother’s home Final arrangements discussed prior to death Dog present Church funeral Burial
Daughter Mia	Father	CA prostate Chemotherapy Natural therapies	No supports	Died in father’s home Final arrangements not discussed Family conflict Cremation
Husband Sergio	Wife	Cerebrovascular accident (stroke)	Family Doctor Community nurses	Died in daughter’s house Final arrangements discussed prior to death Conflict with funeral director

The participant profile summary provided a simple portrait of each research participant, gradually evolving into a representation ‘for the group of participants collectively’

(Moustakas 1990, p. 49). It was in this act of the research process that I commenced the early stages of coding, which involved:

the marking of segments of data with symbols, descriptive words or category names, dividing the data into meaningful analytical units (Willis 2006, p. 266).

The following section of this chapter identifies the six stages of coding identified by Beanland et al. (1999, p. 345), which demonstrates the iterative, generative nature of the research process.

- **Familiarising Myself with the Research Data**

This stage of the research involved thoroughly reading each participant's transcription, reviewing my journal notes, research memos and personal correspondence. By reading and re-reading the data, further insights became apparent. Immersion involves being saturated with the research data and encountering the information in an active way, such as reading, re-reading, thinking about meanings, talking to people about the process and accumulating copious data. In the incubation stage of heuristic enquiry, the researcher deliberately moves away from the data for a period of time to clear one's mind. This can be a time when new insights emerge at times least expected. I found that it was important to have a pen and paper handy, particularly at 3.30am when I would wake with a new idea. Explication was a deeper examination of the data that came to mind from examining the various layers of meaning in the different themes.

- **Identifying Shifts in Participant's Thoughts and Dividing the Transcription into Different Thought Segments**

At this stage I actively started making sense of what was presented in the data by means of organising items into segments. A challenge of this stage was to retain the context in which each thought segment was located. According to the heuristic enquiry approach, this stage and the following stages of my thematic analysis are described as illumination and explication.

- **Highlighting Significant Statements in each Segment which Describe the Experience**

A close scrutiny of each thought segment was required to identify specific statements of experience in participants' quotations. My copy of each participant's transcription was bound and I inserted between each page of the typed transcript a blank page for the purpose of writing memos. I used a highlighter pen to underscore any segments in the transcript which I considered were significant, and I wrote notes on the blank page relating to people's lived experience.

- **Distilling Significant Statements into the Words of the Researcher which Express the Core Meaning of the Thought Segment**

At this stage of the thematic analysis, I paraphrased and reflected the meaning of participants' thought segments and applied codes on the blank page of the transcript to identify the core meaning. Braun and Clarke (2006, p. 88) differentiate codes and themes on the basis that themes 'are where the interpretative analysis of the data occurs and in relation to which arguments about the phenomenon being examined are made'. I met with one of my research supervisors to discuss and critically reflect upon the codes I had created. At these meetings, I was challenged about my assumptions and interpretations and these meetings served 'as a sounding board for ideas' (Cresswell & Miller 2000, p. 129) that developed throughout the analysis.

- **Initial Synthesis of Core Meanings of all Thought Segments for all Participants, Focussing on the Question being Studied**

Forty-five inductive codes were generated from the segments, which were collated for the purpose of generating themes. A thematic map was used to sort the different codes into different themes. This process enabled me to consider the relationship between the codes and themes (Braun & Clarke 2006, p. 90) and to review the coded statements from the participants to determine the relevance of each theme.

- **Final Synthesis of the Meanings that have Emerged in all Participants' Descriptions Resulting in an Exhaustive Description of the Lived Experience**

From the forty-five codes, twenty-four categories were identified and eleven themes were used to describe the lived experience of the participants in the study. One fundamental theme was woven throughout all of these themes. Braun and Clarke (2006, p. 93) consider this stage as being the one which allows the researcher to write up the report because sufficient evidence of the themes has emerged from the data. In qualitative research, the process of member checking is often used for verification, a qualitative nuance of the term *validity*. This procedure involves the researcher taking the 'data and interpretations back to the participants in the study so that they can confirm the credibility of the information and narrative account' (Cresswell & Miller 2000, p. 127; Moustakas 1990, p. 33). While I used this process for verifying the accuracy of transcripts, I decided not to engage in member checking at the time of analysis for a number of reasons.

First, retelling the experience of attending the death and being involved in final arrangements for a significant other person can be distressing. To return to the participants to ask them to check the accuracy of the themes I created and comment on 'whether the overall account is realistic and accurate' (Cresswell & Miller 2000, p. 127) was deemed intrusive. Second, some people were not interested. My decision not to engage member checking was supported by an encounter I shared with a participant whom I spoke with some time after his interview. Below is a journal entry I recorded in relation to that meeting:

Wednesday 23rd November 2005. Some days after the interview, [name] shared with me that he remembered some bits of his story which he hadn't included in his initial interview. When I asked him if he would like to include them by being interviewed again, he said 'no'. When I asked him if he would like to write down what he had remembered he said 'no'. He said that he was happy with what he had said and didn't want to think about the experience anymore.

My decision was endorsed by another participant who expressed her lack of interest in being consulted about the accuracy of the themes. Third, while the issue of avoiding the

potential of harm resolved my decision not to include member checking, the social constructionist paradigm underpinning the study added weight to my resolve. Talburt (2004, p. 81) states that:

qualitative inquiry has a grounding in 'real' events and 'real' lives but learning about and representing events and lives is a process of constructing others' constructions of the constructions of the world.

The themes I constructed were my interpretations from the shared experiences of people. I decided to exercise control over the interpretative process, taking responsibility for the process, and thereby claiming full accountability for my findings. The final section of the research methods below addresses what I did with the knowledge generated from the study.

Dissemination of the Research Findings

The dissemination of the research findings has been described as 'putting the show on the road' (Roberts 1984, p. 199), referring to the process of 'elevating those findings from the filing-cabinet drawer and into the consciousness of others', (Roberts 1984, p. 200). My methods of dissemination involved the following procedures. Participants would be offered either a copy of the entire research document or the findings chapter. Contact with the *Examiner* newspaper was made, and an article published that reported on my research. I was asked by my current workplace to present a paper for National Palliative Care Week, at which more than thirty people attended, from a variety of community organisations. In July 2008, the 8th International Conference on Grief and Bereavement In Contemporary Society was held in Melbourne, titled 'Consequences of loss: resiliency and complications in the grief experience', and I submitted an abstract for this conference to present the findings, and my submission was accepted. I presented a paper to the audience titled 'In life, death matters'. My future plans include the publication of several journal articles following the submission of this thesis.

Concluding Comments to Stage 2

Throughout the immersion phase of my enquiry several research processes were employed to inform the research question, ‘What are people’s experiences of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness?’. These processes included a review of the research literature, the methodology and the research methods.

Chapter 3 examined the research literature demonstrating how the lived experience can operate in variance to the ideology of a good death, subsequently impacting upon peoples’ grief journeys. Also highlighted was the dominant narrative of risk and negative outcomes eclipsing the strengths of people operating at a time when fatigue and loss coincided with the demands of important decision making at end of life.

In chapter 4, I presented the methodology employed as a framework for the methods used to gather and analyse the data. Subjectivity is at the heart of this study and my values as the researcher are regarded as integral to the research process. Using a qualitative approach to generate understandings of a socially constructed world meant that I attached importance to people’s lived experience. Consequently, relationships were considered an essential feature of this enquiry. Furthermore, I realised that ethics was an integral aspect throughout the entire research process and that this study was yet another intervention of social work practice. Employing an heuristic design was a purposeful and deliberate strategy to align the philosophical and practical aspects of my study, evident by the synergy between my engagement with the theory and my positionality in relation to the participants. Employing this particular research design brought many unexpected outcomes, which are described in the following stage, incubation.

Stage 3: Incubation

Incubation is the process in which the researcher retreats from the intense concentrated focus on the question. Although the researcher is moving on a totally different path, detached from the involvement from the question and removed from awareness of its nature and meanings, on another level an expansion of knowledge is taking place (Moustakas 1990, p. 28).

This section of the thesis reports on the incubation stage of the enquiry. In chapter 5 I expose a selection of the challenges which arose from the dual process of being immersed in the topic of death and bereavement and the decision to employ an heuristic research design. I claim that the act of disengaging from the enquiry helps to sustain the exploration of a sensitive topic and does not equate with abandoning the research endeavour. I also communicate how it was during this stage of the enquiry that I came to terms with compassion, love and care that permeates the experiences of the research participants.

Chapter 5: Doing Research on Death and Bereavement

Introduction to the Chapter

In the last decade, the challenges that face the investigator doing qualitative interviews on sensitive topics have been highlighted throughout the research literature (Beale et al. 2004; Dickson-Swift et al. 2007; Lalor, Begley & Devane 2006; Rowling 1999).

Examining this small body of research informed me that there is 'very little empirical work focusing directly on the experiences of researchers' (Dickson-Swift et al. 2007, p. 329). What research is available concurs that qualitative researchers face a number of challenges (Beale et al. 2004; Dickson-Swift et al. 2007; Lalor, Begley & Devane 2006; Rowling 1999). The following section of this chapter highlights the challenges I encountered and my conscious ploy of disengaging from the enquiry as a means to sustain my continued involvement.

Being Invited into Private Spaces

Throughout this enquiry, I developed a greater understanding of what it means to engage in social work research investigating death and bereavement. Although I had been working as a bereavement support worker for several years prior to commencing this study and I was confident in my ability to support a person if they became distressed throughout their interview, I underestimated the impact of being a researcher of death and bereavement. Listening, reading, transcribing, re-reading, re-listening, analysing, re-examining and plunging many times again, deeper into the stories of people's loss was an experience unlike that of being a bereavement worker. Undertaking research in death and bereavement presented me with a number of challenges, which sometimes prompted me to reconsider some of the assumptions I had made, as well as forcing me to reassess my own worldviews. This became evident when several people I knew died throughout

the lifetime of this thesis, bringing matters of death and bereavement very much again into my own private life. Attending people's funerals made me not only mourn their loss but gave me the opportunity to consider more profoundly the plight of family members and significant others in their very early days of bereavement. I also experienced the death of our dog during this study, which had been a loved companion to my mother throughout her dying. The significance of this event impacting upon my research practice was recorded in the following journal entry:

I didn't feel like interviewing today because our little dog Polly who we have had for eighteen years died last night. I phoned [-] in the early afternoon to confirm that it was still alright for me to come, (secretly hoping that [-] would say that it wasn't convenient), but was told that afternoon tea was awaiting my arrival. When I presented at the door, [-] had a little dog tucked under her arm. [-] asked me whether her animals, including two well loved cats, would bother me. I assured her that they wouldn't and that it was nice to have their company. I realised then that (-) loved her pets so I felt safe enough to share the significance of Polly's death with her, explaining that Polly had been a comforting and constant reminder of my own mother's presence. [-] was very understanding and empathic when I disclosed the relationship I had with Polly. I found this interview not as long in duration in comparison to the previous interviews but it was very emotional. After I turned the iPod off, [-] left the room and returned with a beautiful trinket box, opening it and showing me a lock of hair she had cut from her mother after she had died. [-] also said that she had dressed her deceased mother in a blue and pink nightdress and later bought a Royal Doulton figurine which her mother had loved. The figurine had the same shade of pink and blue as the colour of the nightdress. [-] said 'Silly isn't it?' and I said that I didn't think it was. We discussed the significance of such acts, giving meaning to remembering and maintaining a bond with someone we love. This interview gave me a strong sense of continuing bonds and reaffirms my belief that grief not only remains with people for a lifetime, but connects people through empathy, despite barely knowing one another.

The research topic dealing with death and bereavement is highly emotive. My journal entries are replete with poignant moments, particularly evident when participants expressed their continuing bonds with their deceased significant other person. The following example, recorded in my journal, is an example of the many which left a marked impression upon me:

At the end of this interview, [-] took me into a spare room to show me the last jigsaw puzzle she had done. I learnt that this had been the room where her husband died. On his bed was a teddy bear and in passing, I commented what a lovely bear it was. [-] said that this was the bear his grand daughter had given him and that he would often embrace the bear when he was feeling miserable. [-] explained that since his death she would sometimes walk into the room and talk to the bear. At that moment, she took the small paw in her own hand and gently shook it, speaking in a soft voice 'I haven't been in to talk to you for awhile, have I?'. And then she looked at me and said, 'It's the finality of it that's so hard'.

In the next journal entry, I noted how a family experienced the tragedy of multiple loss, having two babies both die from a life limiting illness:

Interview with [-] and [-] who had two infant daughters die at home. These parents had no history of this particular disease in their family and so the diagnosis was a shock when their first daughter was diagnosed around 10 weeks of age. After the death of their first daughter and the conception of their second child, having been tested and told that the results were negative and their child would not suffer the same plight, [-] and [-] discovered that their second baby was born with the same disease. These babies both died at home and remained with their family for several days until they were transported in their parents' car to their funerals. Their father also built their coffins and he dug their graves in the local cemetery. I drove home from this interview stunned, with a sense of awe and reverence for this family who demonstrated extraordinary wisdom throughout a time of indescribable grief.

During the immersion stage, I also learnt that several participants in this study were suffering degenerative health and three others divulged that people close to them had recently been diagnosed with either chronic or life limiting illnesses. The weight of sadness I sometimes felt was offset by my feelings of respect for people's demonstrated courage and resilience.

[-] explained that despite himself having been diagnosed with cancer five years ago, his wife was diagnosed after him with a different type of cancer and she died nineteen months following her diagnosis. Together they helped to set up a cancer support group. [-] described how his wife's death has created an enormous void in his life, yet he has been able to draw on his inner strength for improving himself, which he explained was done for the purpose of restoring some control in his life. [-] has done this by confronting his own fears and has attended grief and

bereavement workshops and male support workshops. [-] has shown enormous courage in the face of adversity and a generosity of spirit, since he was obviously not well when I spoke with him today. [-] shared his concern with the approach of Easter, explaining how festivities and holidays will often intensify his feelings of isolation and loneliness.

Many times I cried with the participants as they recounted their experiences, and just as often, I would weep as I transcribed their stories. I remember on one occasion being collected by my partner from a café after meeting with a participant. As soon as I got into the car, and drove away, I buried my head in my hands and sobbed and my partner asked with a worried look on his face, 'How many more interviews will you do?'. But crying did not worry me because I have learnt that it is a way that I manage my sadness. I knew that I needed to be composed with participants, but this did not prevent me from crying with them. What I did consciously prevent from happening in an interview was allowing my sadness to remove the focus away from the person telling the story. It was in my own private spaces that I openly expressed my sorrow, and this I did on many occasions. I also believe that allowing myself to cry was an effective strategy for emotional relief.

I was asked on several occasions by people enquiring about my research whether I had developed a morbid attitude to life. I replied, 'often to people's surprise, that while my research had instilled within me a strong sense of impermanence, it had also added lustre to my life. Having self-awareness of being mortal offered me a constant reminder that life was to be lived. A research participant who wrote to me throughout the research journey shared a similar attitude. In one of her letters, she explained:

More and more as each day passes, I realise that every part of life is a gift not be taken for granted and all the special 'little things' like the birds singing and feeding their babies, the moon on the water, the love of family and friends and so many other things are really what life is all about and I hope that now I notice those moments more and stress less about unimportant stuff.

One unexpected outcome which emerged throughout the research process helped to broaden my understanding of paranormal experiences. Throughout the period of

interviewing and transcribing I occasionally felt the presence of someone. The following entries in my journal describe how this occurred on several separate occasions.

11.10 pm. Sitting here transcribing and yet again I feel the presence of someone behind me. I know that I can't explain it rationally. It feels like a male presence. I don't feel frightened by it; distracted maybe and a little uncomfortable, but not scared. I recall that this experience has happened before.

1.50am. A couple of times tonight while I was transcribing I felt someone watching over my shoulder. A presence was felt strongly enough that I turned around to see whether one of my boys was standing behind me, having woken from their sleep. No-one was there. It seems to be a curious sort of presence rather than anything alarming. Maybe this is about forming connections with the deceased through the lives of the participants.

Being employed as a social worker in the field of palliative care, in addition to researching death and bereavement, meant that I would sometimes make the conscious decision to remove myself from focusing on matters of end of life. Detaching from the research process was not a means of abandoning the research endeavour. Going on holidays and being with my friends and family were activities I not only enjoyed but helped to put death and bereavement into perspective. Disengaging was necessary to prevent death and dying from becoming my sole focus in life. A ramification of disengaging meant that the research process took longer than I had anticipated; however, I learnt that the process could not have been hastened and that a deep and passionate exploration of this research topic demanded that I be patient. I also learnt that in the process of heuristic enquiry I needed to place value on the journey and not solely on the destination. I also learnt that it was from these moments of disengagement that I could sometimes gain greater insight to my research question.

I learnt to write down ideas for my thesis when I woke at night as I could not remember these same thoughts in the morning. These ideas would often appear in my semi-state of consciousness and would disappear again by the time I awoke again. I also realised that speaking with people informally about my research often allowed unforeseen opportunities for me to articulate what I was doing, enabling me to coherently communicate my ideas. It was via one of these informal conversations with a research supervisor that I explicated the core discovery of this thesis, realising that at the heart of

people's experiences was a story of a close relationship given expression through compassionate love.

Concluding Comments to Stage 3

This chapter has described how unexpected findings can emerge throughout the research process, potentially when a researcher's focus is not directed on the research question. The essence of heuristic enquiry is being open to new discoveries, not only from the data provided by research participants but also from the 'data within' (Moustakas 1990, p. 13). In the following pages, the stage of the enquiry known as illumination is presented, highlighting the findings from my encounters with the research participants.

Stage 4: Illumination

Illumination opens the door to a new awareness, a modification of an old understanding, a synthesis of fragmented knowledge, or an altogether new discovery of something that has been present for some time yet beyond immediate awareness (Moustakas 1990, p. 30).

This section of the thesis reports on the illumination stage of the enquiry and comprises chapters 6, 7, 8 and 9. Chapter 6 describes the impressions I formed from my encounters with the research participants. I also introduce the research strategy chosen for reporting the findings. In chapters 7, 8 and 9, I answer the research question, ‘What are people’s experiences of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness?’. The overarching theme which emerges from each chapter tells a story of a close relationship given expression through compassionate love.

Chapter 6: Bringing People To Life

Introduction to the Chapter

In this chapter I present a profile of the research participants and the significant other people who died at home. The purpose of this profile is to bring to life the people who shared their experiences for this study who would otherwise exist only as a number affixed to the end of a quotation. The final section of this chapter documents the reporting strategy for the findings of this research.

Introducing the Research Participants

Twenty-eight people narrated their experiences for this study. People identified themselves in their stories as being the *wife* (n = 11), *husband* (n = 2), *sister* (n = 1), *daughter* (n = 8), *mother* (n = 4), *father* (n = 1) and *family friend* (n = 1) of the person who died. Though the selection criteria for this study demanded similar attributes from the participants, the people who shared their experiences were not a homogenous group. There was considerable diversity amongst people's ages, backgrounds, health status and lifestyles, and while some people voiced a strong religious faith, others declared no religious affiliation. Ten people attended to the death of a significant other person in a home which was not their own, sometimes moving a considerable distance away from their own residential address, while the remaining eighteen people lived in the same home with the person who died. Seven people attended to the death and final arrangements outside of Tasmania. 25 of the 28 participants in this study were female, suggesting a similar trend to the national statistics indicating that the majority of people caring for terminally ill people in Australia are women (Palliative Care Australia 2004, p. 13). From a gender perspective, many males may choose not to respond to qualitative studies thereby serving to under represent their contribution, however the overall impact upon women's financial, physical, social and psychological wellbeing cannot not be overlooked.

Most participants expressed concern that their story would be of no value to this study. These participants believed that their experiences were nothing remarkable although they recognised that their own experience had made a lasting impression upon them. The impetus for the majority of people to participate in the study was a common hope that their lived experience might offer a greater understanding to the general community of what it means to support a significant other person to die at home. Many people also spoke in honour of the person who had died, believing that the deceased would want to have their story told for the benefit of the wider community.

Meeting and speaking with each participant was a richly rewarding experience. Some people cried at the onset of their interview, others appeared relieved when the interview came to a close. Some people explained that their interview enabled them to recall humorous and intimate moments at the time of death and throughout final arrangements, despite describing the overall experience as one of the greatest losses in their lives. A number of people wrote letters after their interview. Letters developed a strong and pervasive presence in my research and it became a vehicle to continue relationships with some participants by exchanging ideas, feelings, thoughts and reflections. Every participant embraced their research role with an astounding generosity of spirit; an experience which remains indelibly imprinted upon my mind.

The people in this study did not portray themselves as super human or capable of achieving heroic outcomes. They spoke about themselves in realistic terms, highlighting their doubts, uncertainties and limitations. These people showed tremendous courage amidst times when fear, despair and anguish loomed large in their lives. They also demonstrated a deep caring for others, evident in their desire to share their stories for the benefit of the community and through their efforts to make me feel comfortable when I met them, either through their kind hospitality or their willingness to answer the questions I asked. A lasting impression of the people who participated in this study was the wisdom that they shared in knowing that they spoke only from their place of experience and not from a position of being representative of everyone. This insight is demonstrated by the following comment:

Every situation is unique I would imagine; everybody processes it differently. 11

Introducing the People who Died

Throughout the duration of this study, I not only became acquainted with the people who shared their stories but also with the lives of those who had died. I was invited to hear details about their dying and their deaths, and I became witness to some very intimate details about their bodies. I also heard about their suffering, their courage and occasionally their faults, which served to make them more human. On occasions I saw their photos; was introduced to extended family members and friends; met their companion animals that survived them; and stood in the rooms where they had died. I also became privy to some very personal items of the deceased that bore significance for the research participants.

A quarter of the participants used memorabilia to communicate information about their significant other person, including personal correspondence, gifts, clothes, photographs, locks of hair, portraits, jewellery, and achievement awards. I was invited by one participant to watch a home video of her mother's birthday celebration prior to her death. I recognised that keeping these items not only helped to rekindle particular memories for participants but they also offered a tangible means for maintaining the deceased person's membership in people's lives. In the following passage taken from an interview, a participant used a photograph album to bring her mother to life:

I made a photo album up and I just wondered whether you were interested in having a look ... Okay. This is my mother. What I did after she died was go through every photo we had and make up this album. This is my little memory bank of my Mum ... That was one of her favourite flowers in one of the gardens and that's the funeral service. But these were the ones taken and she died ten days after they were taken... And these are all photos of my Mum throughout her whole life. So, I've got this record of her having holidays and all that, so just all these nice... There's one of her wedding here... These are different houses she lived in. That one there is in [the place] where she grew up as a child.

4

The dead people in this study include ten husbands, two wives, one adult sister, six fathers, three mothers, one adult female family friend, one adult daughter, one teenage daughter, two infant daughters and one young son. Two of these people had been dead for approximately twenty years, although the majority of people had died within two to

sixteen years. One person had been dead for less than a year since the time of interviewing.

The predominant causes of people's deaths in this study can be attributed to varying types of cancer, although heart disease, emphysema, diabetes, cerebrovascular accident, and spinal muscular atrophy were also cited as other diseases causing premature death. In one instance, a person had endured a long history of mental illness prior to being diagnosed with a life limiting illness and another person had suffered chronic health problems for more than fifty years following his return from World War Two.

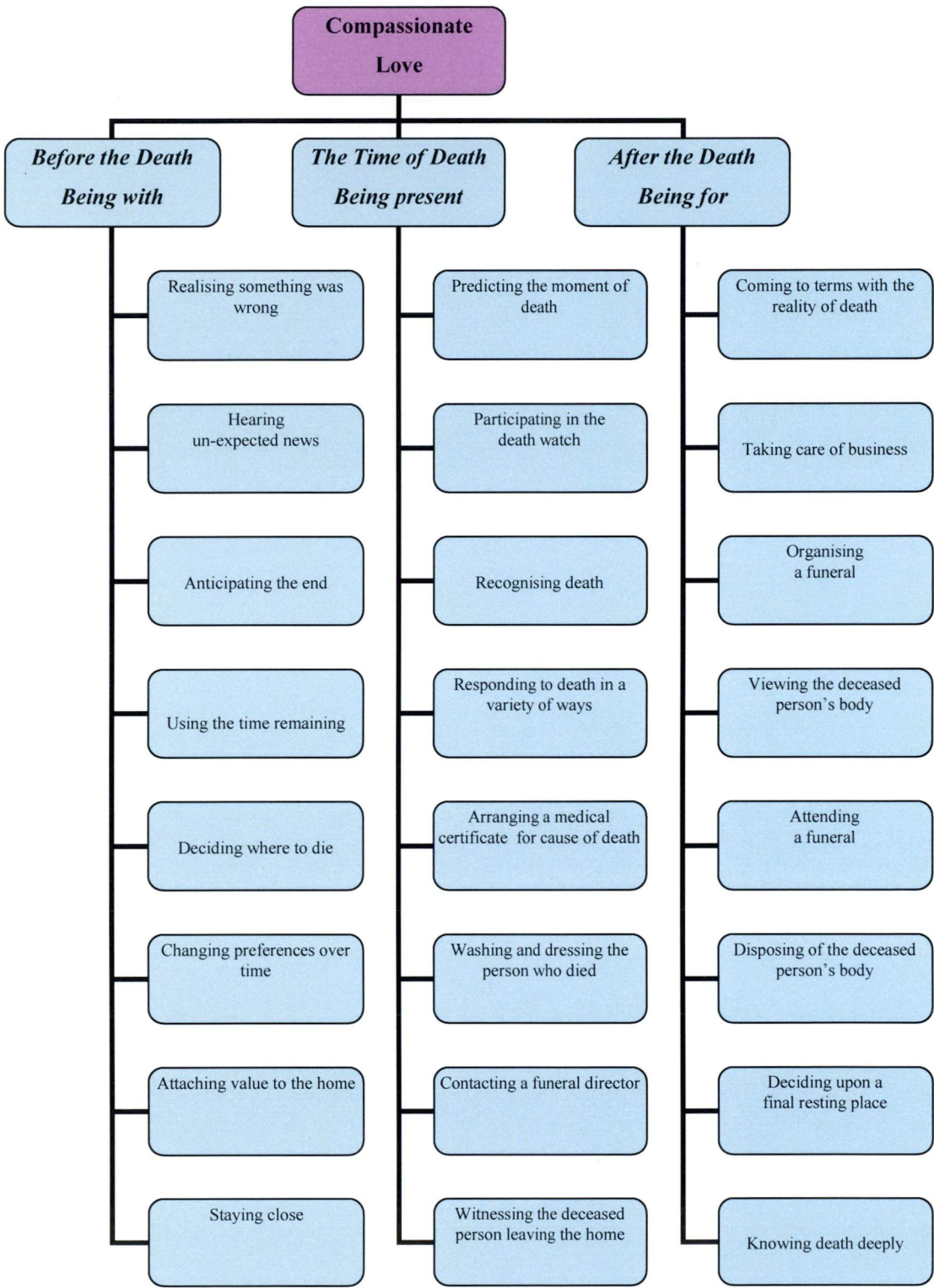
Reporting Strategy

The reporting of the findings has been organised as events told over time under the rubric of three different periods. These periods are known as 'Before the Death', 'At the Time of Death' and 'After the Death'. A further analysis of people's experiences illuminates a key theme in each period, evidenced by the data sourced from participants' experiences. In the period 'Before the Death', the theme of 'Being with' was identified. This is a time when people commit to their relationship, subsequently witnessing the disease progression and the process of dying. The period referred to as 'The Time of Death' brings to light the theme of 'Being present'. Throughout this time, people companion their significant other person as end of life approaches, ultimately bearing witness to their death. In the final period, After the Death, the dominant theme to emerge is 'Being for', whereby people act on behalf of their deceased significant other person, honouring their wishes and memorialising their life. A deeper analysis of all of these themes illuminates a common thread woven throughout the temporal and experiential dimensions, identified as the overarching theme of compassionate love.

The themes are reported as temporal phases which reflect the organisation of participants' thinking. Participants' narratives are based on the key activities of each phase of their experience. The themes are supported by a selection of excerpts from participants' narratives. Each excerpt concludes with a number which corresponds to the number assigned to each participant's transcript. The examples are not intended to be an

exhaustive depiction of every person's experience. They are chosen on the basis of being able to portray various dimensions of a common or unique experience. The relative frequency of the ideas presented in each experience, variations of the experiences and disruptions to the data are presented in the findings. In the reporting of the findings some of the quotations are long and I have sought to use minimal commentary. These are deliberate strategies to enable the power of the data to emerge through the words of the participants. The following figure (Figure 1) illustrates how these key themes operate, showing the eight categories identified in each of the three themes.

Figure 1: Participants' Experiences

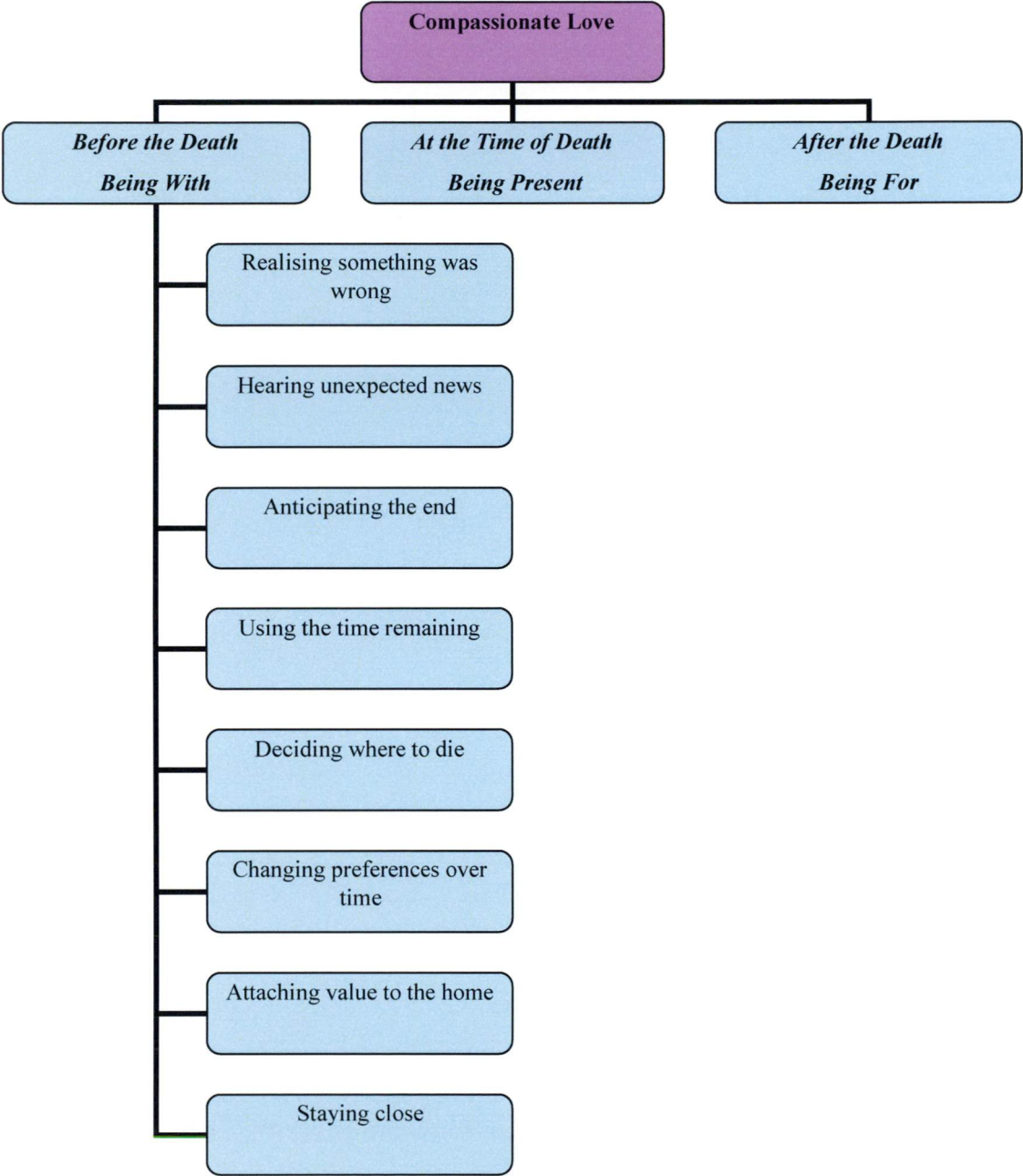


Chapter 7: Before the Death — Being With

Introduction to the Chapter

The temporal period known as 'Before the Death' is referred to experientially as 'Being with' and is relevant to this study because it locates death within a specific context. This period commences when a significant other person is diagnosed with a life limiting illness but it may also be foreshadowed by knowing that the person had been unwell for some time. Some people spoke of having had no knowledge that any illness existed prior to the diagnosis. Consequently, this period varies in duration because the knowledge that something was wrong may have been apparent for either for a brief while or for a long, protracted period of time. 'Before the Death' ends when a person is aware that vital signs of life are fading or have ceased to exist. The following figure (Figure 2) illustrates the different categories of participants' experiences throughout this period.

Figure 2: Participants' Experiences Before the Death



Realising Something was Wrong

Two different aspects of people's experiences became evident in the category of realising something was wrong. Almost three-quarters of the participants explained that the diagnosis of a life limiting illness did not come as a surprise because people were either aware that 'something was wrong' or that there had been a long history of illness.

Some people explained that they thought their significant other person had been unwell prior to being diagnosed with a life limiting illness:

It started with him not feeling well. His joints ached and just not right. He was a very strong, robust, energetic person and he was starting to feel not himself. He went to the doctor and the doctor told him there was nothing wrong with him. 17

People often used the word 'wrong' to imply poor health. Suspecting something was 'wrong' often continued despite sometimes receiving medical advice to the contrary:

In September they said that he was okay, but he was really in a lot of pain and we knew something was wrong. 2

The time span in which people were unwell varied and several participants explained how their significant other person had endured a long history of chronic illness continuing for more than two decades. The findings from the data indicate that a fifth of the people diagnosed with a life limiting illness recognised insidious disease progression for more than several years. In the following quote one of the participants highlights her memory of her husband's protracted disease history, eventually culminating in a life limiting illness:

He had been suffering from various sorts of mental or psychiatric illnesses; depression; nervous breakdown and general ill health for most of our married life. The children wouldn't remember him as ever being well. In the last twenty years, if we went a year and he didn't have two hospital visits, that was abnormal. So we'd known a long time he was an unwell man. Two years prior to his death he had a major heart attack and was in a coma for three weeks and had major bypass surgery. 15

Another participant chronicled her husband's illnesses beginning in 1941, the year her husband joined the navy. She wrote that hepatitis, dermatitis, diabetes, ulcers, arthritis, heart disease, haematomas, bladder cancer, kidney cancer, twisted bowel, and associated complications such as weight gain, cartilage deterioration and uncontrollable bowel motions were just some of the conditions that her husband suffered, noting that:

From time of returning home, his health problems dominated most of his life. 14

Hearing Unexpected News

Whereas some participants thought that it was possible that their significant other person might be diagnosed with a serious illness, others reported that they were unaware that their significant other person was unwell. When the news was unexpected, participants explained that the diagnosis of a life limiting illness came as 'a huge shock'. Participants explained it was like a 'bolt out of the blue', 'a nasty surprise', and 'just to have this thrown at you, it was very, very sudden'. In these cases, people said that they 'didn't expect that at all'.

Disbelief and shock were commonly described as responses to the unexpected news of a life limiting illness. One participant explained that the experience was 'like a rollercoaster emotional ride'. One example of the utter disbelief experienced by a quarter of the participants in this study is highlighted in the following excerpt taken from a mother's narrative. This participant recalled a conversation between herself and her husband concerning their teenage daughter. The conversation occurred while the mother was overseas on holidays:

I said, 'Well, what's wrong with her? There was nothing wrong with her the other day when I left on Sunday'. He said, 'She's got leukaemia'. I said, 'Oh, don't be silly!' Well, what would you expect? This kid's fit and healthy and then, bang; like that! He said, 'You'd better get home quick. The doctor's given her three days'. 19

Anticipating the End

Finding out from the doctor that death was an inevitable outcome from the disease meant that people's lives were suddenly changed. Some people contemplated and discussed what lay ahead and how much time remained for their significant other person. Although participants explained that being told the prognosis was an awful experience, they also appreciated being given a realistic indication of how much time remained. In the following excerpt, a woman describes a conversation between her husband and his oncologist:

[My husband] was very straight forward, he said, 'Alright Doc. I'm tired of this. I want you to tell me what the situation is'. And poor [the oncologist], not knowing us, and not having been on the scene the whole time, just stared at the floor which I swear seemed like an hour and finally said, 'The situation is this', in medical terms and he said, 'I hate to tell you this but you probably have a few months; maybe six months'. And I thought; like your heart just fell onto the floor. It was good because at that point we knew what we had to do. We knew that we could stop fooling ourselves and thinking that we would have a year and that we had time to say these things and time to do these things. So it was, like I said, really, really the hardest thing; the last thing you want to hear but it was so important for someone to say that to us.

17

Some doctors and medical specialists chose not to predict what time remained, knowing that disease progression could vary extensively between individuals. This reserve is encapsulated in the following quote:

I was so worried about the long term situation ... he was just full on care really and we had made an appointment to talk to [our doctor] about Dad and Mum and about what our options were and he said it was really hard because he didn't have a crystal ball either.

7

Learning of the prognosis meant that people had to confront the stark reality that death would be an inevitable outcome. This realisation usually brought with it a sense of foreboding loss. In the following example, one participant recalls how she dealt with her mother's candour in the site of the hospital:

I was thinking I'd just get her home and she'll be alright. She said, 'I want to go home. I don't want to be here. I don't want to die here', and I remember she was in a four bed ward and I burst into tears and ran into the toilet and she yelled out to me, 'Don't cry. I'm not dead yet'.

8

The next example in which a participant realises that death would eclipse life comes from a husband's narrative in which he recalls a conversation he had with his dying wife. The extract strongly conveys the love they shared and reveals the deep emotions that the memory of the moment continues to evoke:

I remember one morning lying in bed together; it's starting to get hard talking about how much we loved one another. She'd accepted at that stage that it was likely that she didn't have long to live and lots of tears about people she wouldn't see again, and lots of grief about not seeing her children grow up and grandchildren arrive. I think in the end she accepted death but she felt cheated because she was going to miss out on all that stuff and she was very much attached to the kids and we had two grandchildren at that stage. 25

Using the Time Remaining

Several aspects emerged around using the time remaining. Knowing that there was no cure for the disease meant that some people began to use the time to achieve specific goals and make changes in their lives, whereas others used the time to plan for the death, particularly regarding where they would prefer to die, and others used the time to make arrangements for the funeral.

Having some estimate of what time remained enabled participants to undertake specific tasks and achieve specific goals as demonstrated in the following comment:

It was fourteen months known and it was surprising what was all fitted into it. 23

A lack of planning and discussion was not synonymous with denying the inevitable outcome of death. One participant described how she did not discuss with her mother any subject concerning death and dying:

She didn't want to know. She didn't want to know about — what did she call it? Clap trap.... No. No. It was an unstated, don't talk about it thing. 24

Despite her mother's death being 'an un-stated' topic, death denial was not evident because this participant realised that her mother had been actively organising for her death by arranging another owner for her beloved pet dog:

She had her little dog there probably until a week before she died. She gave that away to a friend. Turned out she'd done a deal with her on the side and had it all worked out. This dear little dog; it was a shih tzu, a dear little thing and she made dear friends with this lady who used to pick her up and take her and groom her. I distinctly remember [she] came to pick up the dog to groom her and Mum just looked at her and said, 'Don't bring her back'. [My mother] just started to cry and she told us later that she had this pact. I'm sure [the dog]'s not alive anymore but we went to see her about a year after Mum had died and they were happy. So she was organised. 24

Four participants in this study explained how their significant other person embraced spirituality before death. People's reasons included a faith in the after-life, support throughout adversity and access to ongoing social support. In the following extract, a woman explained how she and her husband embraced Christianity:

We did go to find Christianity together as a couple and you'd have to say that as a result of that and as a result of us going to church every Sunday, that had significance because that's right, it's all coming back, the church as a fellowship prayed. 10

Several participants spoke about how they attended to the haircuts or pedicures of their significant other person before they died. One participant recalled a conversation she had with her father who wanted to have his hair cut before he died:

He said, 'Well, I've got to have a haircut before I go anyway'. I said, 'Well, alright, we'll get you a haircut', so I rang the barber he used to go to, and he came out, [name], I'll never forget it. He came around and we sat him outside at the pool and he cut his hair and all the rest of it and he said, 'Now you can go to heaven looking pretty'. So he was happy then. He had a haircut Marg. He was right. 21

Enabling their significant other person to achieve their personal goals was important for the participants in this study, demonstrating a respect for their close other's uniqueness and individuality. One of the goals identified by participants in this study was the

preference of the person with the life limiting illness to die at home. One mother explained how her young son's prognosis acted as a catalyst for making a critical change:

[Our son's] death would be inevitable within the foreseeable future. We sat there in stunned silence weighing up what had just been said but we really knew that our decision would be to take [our son] home. We felt that over the past two months he had undergone more than his fair share of needles and tests and that if he was going to die then it should be at home with dignity and peace. The doctor left us to ourselves while he went to tell [our son] what he had just told us (except for the fact that [his] death was inevitable), and [our son] made his feelings evident immediately as he had no hesitation in taking the choice of going home ... [Our son] came home that afternoon with his collection of books and games which he had been given by his visitors over the past two months, and with his small supply of medication. We said goodbye to the nursing staff and turned our backs on what had been [his] home for eight weeks. We had made our decision to have him home until the end and apart from two or three unplanned short hospital stays over the next three months, this we were able to do.

27

Deciding Where to Die

The reasons given by participants in this study for enabling their significant other person to die at home from a life limiting illness are diverse. Making the decision to die at home is founded on a complex medley of reasons and in some cases, the reasons are never actually articulated, nor are the actual implications of enabling a person to die at home discussed or considered. For other participants, the resolve to facilitate their significant other person's death at home was discussed at length and planning was comprehensive. Consequently, three aspects of people's experiences were recognised: no discussion with anyone; discussion with people other than the person with the life limiting illness; and open discussion.

In the first instance, some participants explained how no discussion ever took place regarding the desire for their significant other person to die at home. These participants spoke in terms of 'Nothing was discussed'; 'He never said what he wanted to do' and 'I think that was an unspoken thing'. Reflecting upon what it would mean to enable their significant other person to die at home, two other participants said, 'I don't even think I thought of the implications of nursing him at home' and 'We never really talked about how we should go about things'. In the following example, one participant describes

how the decision for her husband to die at home was made by the hospital staff without any consultation between herself nor her husband:

[The hospital staff] just said, virtually, 'There's nothing we can do for you, go home'. 11

This participant explained how having no money and being totally dependent upon the public health system located many miles away from their home created a very stressful experience: 'there was no body there; no family; no supports'. She describes having felt 'very isolated' while she cared for her husband at home and wondered why there was never a discussion between herself and the hospital staff prior to his discharge about what it would mean for their quality of life.

In the second instance, a quarter of the participants in the study explained that the goal to die at home was discussed with people other than the person with the life limiting illness, as demonstrated in the following two examples. In the first example, a participant explains how a conversation with her mother about her father no longer being with her gave rise for the opportunity to speak about the decision to die at home:

She said, 'I can't imagine him not being here' and I said, 'No, I bet you can't'. You know, she was pretty weepy, and my sister and I, we were not. Just sort of sat there and said, 'Well, what do you want to do? You've got some really important decisions to make'. 1

In the next example, a daughter explains how she learnt of her father's dying and the role she was asked to take on throughout his end of life:

One of my cousins rang up to say, 'Your Dad's not well and he doesn't want to die in hospital and he wants to go home, and he'd like it if I came back to [the place] and looked after him'. 5

In contrast to these findings, other participants explained that the decision to die at home was a topic which was given careful consideration and discussed. Just over a quarter of the participants understood that their significant other person wanted to die at home because the person with the life limiting illness articulated this goal:

Well, my mother wanted to die at home. She specified she really didn't want to go into hospital... 4

In the next example, a mother explains how her daughter expressed her desire to die at home and how she regards it as her duty to care for her daughter:

She said, 'I want to go home'. She said, 'Is that alright mum?' I said, 'Of course it is darling'. I wouldn't have had it any other way. I mean, whatever she wanted, that's what she got ... I just didn't want her to go to hospital. I mean she had the option. She could go if she wanted. But why should someone else care for my daughter when I could care for her? She was my daughter, and you'd do anything for your child. 19

In the final example, a daughter describes how the decision was made for her father to return home from hospital and be cared throughout his dying, in collaboration with other members of his family:

It was around that time, when I think he might have been able to come home for a few days, at the very end of December, because he was well enough. My sisters were at home as well and they're both nurses and we were all sort of taking shifts to look after him and I thought, 'Oh no, I don't want him to go back into hospital,' and I knew it wasn't about what I wanted. I said to the girls, 'What do you think if we keep him at home? Why don't we keep him at home? What do you think? Do you reckon Mum will want it too?' So, we asked her and she said, 'Yes please. Yes please.' Then we asked him too and he said, 'Oh yes. I want to stay home.' So that was when everything was put into place for him to stay at home. 18

Changing Preferences over Time

The majority of participants explained that their significant other person needed hospitalisation throughout the trajectory of their illness. Almost a quarter of the participants in this study spoke of how the goals and plans of where their significant other person would die were reassessed, particularly when pain and symptom management became critical issues. A family friend supporting a young woman to die at home described how, in the end stages of life, discussions occurred about the most appropriate place for the young woman to die:

It had been discussed. [-] had spent on and off three years in hospital. She absolutely hated the thought of going back into hospital. She loved her own little home and wanted to stay there as long as she possibly could. There was discussion of her going into the [hospice] in the last week before she died, because she was having a lot of pain but [her mother] knowing how [her daughter] felt about going to the hospital and lots of further treatment; she just asked could she be treated at home, could they treat her at home and care for her there? 6

Four participants in this study explained that the decision to die at home was not a priority at the onset of the person's dying trajectory. Two people explained how their significant other person did not initially want to die at home. One participant recalls an episode of visiting a hospice with her sister and brother-in-law.

She didn't want to die at home; definitely didn't want to die at home, so we even went out to the [hospice] together and that was probably the most traumatic thing I did throughout that time, which probably sounds silly but her husband and I went out with her to the [hospice] and we wandered around this place, being told what would happen. It was devastating and it was to her too. She didn't often break down but oh my hell, she broke down that day and I said to her, 'But you don't have to come here. I've told you I will nurse you'. 26

Some time later, her sister changed her mind about not dying at home, influenced by a brief conversation between herself and her young son, bolstered by the assurance from her sister that she would stay with her throughout her end of life. This conversation is also an example of the open discussion between people presented in the previous category of 'Deciding where to die'.

At one stage she was home on the deck and we were sitting out there and she was smoking out there and something was said about the [hospice] and [-], her little boy, just looked at her and said, 'I don't want you to go anywhere to die,' and she said, 'Why [-]?' He said, 'Well, I want my voice to be the last one that you ever hear and if you're out there, I mightn't be there' and with that he went off to play. That's how he coped. It was no big deal. She was quite emotional and I said to her, 'How do you feel about that?' and she said, 'Well, if that's what he wants. What about you?' to me and I said, 'I'll stay with you. You know I won't leave you. If that's what you want, I'll stay with you. I can look after you'. So more or less from that minute on, there was never a mention of the hospice again. 26

One other person who did not initially plan to die at home felt safer in a hospital environment under the surveillance of nursing staff with medical expertise. His wife explained the transition in making the decision to come home:

There was a point where he felt safer in hospital. I mean, he wanted to come home but he felt like if anything happened, the nurses were there for the pain. There were a lot of reasons, I think, fear wise, he felt safer there. In the end he made the decision to come home ... I think after a point, being in the hospital, he just felt like, like it's being away on a holiday. There is a point where you just want to be home because it's comfortable; it's there and I think he wanted to be with me. He didn't want me to have to come and go. I think he was feeling a bit more comfortable with his situation. Maybe he was feeling more stable in his medication but he was very concerned that I get the list and that I was sure that he got all of his medications. 17

Participants did not always know whether they had made the right decision to support a significant other person to die at home. Some of the reasons why people changed their preferences over time were due to feelings of doubt and uncertainty:

I must admit as the days went on, we did question a little bit about whether we were doing the right thing 16

The following example demonstrates how participants questioned their capacity to deal with what lay ahead:

You go through all the motions of thinking about what's it going to be like when they're not here. What's it going to be like towards the end? Am I going to make a fool of myself? Am I going to cope with this? 21

Exhaustion was often the catalyst for doubting whether people could sustain their efforts to enable a person to die at home, shown in the following quotation.

I mean there were times when I got, you know, it's terrible but you get to the stage where you're so tired and I actually said to him a couple of times, 'Look (-), I don't think I can cope with this anymore and I truly think that you could maybe have better treatment in the hospital. They could give you more drugs,' or more things you know; put him on a drip that I wasn't able to do. And he got cross and said, 'Well, do it if you have to', so you knew that you couldn't. 2

The decision to die at home was a choice that most people made. Only one participant's experience demonstrates a disruption to the data. This participant was told by hospital staff to take her husband home to die, and was unable to get support at end of life due to her husband's sudden deterioration:

I was on the verge of taking him back to the hospital because I just didn't know what was happening. He went down very quickly the last time that he came back and I was going to ring and say, 'Please help me. I need help,' but he haemorrhaged that late afternoon, and I didn't get him back to hospital in time. 11

Participants were able to identify a range of reasons why their significant other person chose to die at home rather than in a hospital or hospice. In the following category, several dimensions of the value that people attached to the home are highlighted.

Attaching Value to the Home

The significance of what the home environment meant for people was discussed by all participants and it became evident that the value of home was multi-dimensional. The reasons for choosing to die at home included not wanting to relocate the dying person to another site, a dislike of hospitals, hospices or aged care facilities, and the qualities that home offered.

Two participants explained that home was the site in which their husbands died because they were too ill to be moved to any other location:

I just think probably he was too sick to be bothered to be moved. I don't think he wanted to go anywhere. He just wanted to stay put ... The sickness he had was unreal. 14

For some participants, leaving the hospital and returning home to die was founded on the knowledge that the hospital setting could no longer offer curative treatment. In the following example, the advice given by a doctor to a participant's mother confirms that she was dying, thereby justifying her decision to leave the hospital:

'You should just go home and rest for awhile', and patted her and then I got her in the wheelchair and I was about to wheel her out to the car and she started to weep uncontrollably ... and I remember the sun streaming in and there's this little old lady in a wheelchair just sobbing her heart out and I remember I knelt down on the floor and cuddled her and there were all these people going past, saying 'Would you like to be on your own?' 'Would you like a private room?' And I said, 'No, we're just having a cry!' She said, 'I just don't want to come back to this horrible place. I'm so glad he said I could go home.' 24

Another reason why people chose to die at home was because of their dislike of hospitals, hospices or aged care facilities. Not wanting to replicate the same experience of another person was cited as one reason to die at home:

After the bad experience in November, he had actually said to us then, 'Hospitals, no, no more, never again, no way, no way.' ... because we'd had that bad experience ... and it was such a disaster, that we just knew that it couldn't happen again. 7

A third of the participants clearly articulated the contrast between being in hospital and being at home. One participant explained that care in an institutional setting had the potential to stifle people's expression:

Even though he was in [the hospice] which was a lovely ward and the palliative care people and the doctors and nurses are wonderful there, it's very impersonal there. It's hard for families to come and go and to have their privacy because you want to cry and you've got an audience, in a way. 18

The hospital was described as being a 'clinical sterile environment', staffed with 'foreign nurses and machines'. One participant wanted her husband to maintain his personhood and regarded his dignity as a high priority in the care she gave him:

There was no way I was going to let him be treated as a patient rather than a person. 10

The site of the home was considered integral for maintaining a person's sense of self-respect and self-worth. In the following excerpt, one participant reflects upon how the hospital environment affects a person's sense of self:

The hospital can be a very dehumanising experience, I think, and you do feel quite trapped. I think when you do have a life threatening illness and you are at that point, at the end of your life and you know you are going to die and you're very sick and ill and constrained in your own body; you feel trapped in that sense, but being in a hospital on top of that adds to that, that trapped sense and that sense of what's worth living for, I suppose.

5

This participant explained that the home environment enabled her father to maintain a sense of identity closer to how he felt about himself before he was diagnosed with a life limiting illness:

I think for Dad it gave him some of his identity back as a person who had a home and familiar surrounds and his garden. You know, more freedom, in terms of, even though Dad was very restricted in his movement, more freedom in terms of being able to watch what he wanted, even though he had a television at hospital, you didn't have people coming in and checking things like his physical status in terms of his blood pressure and temperature and all that kind of stuff and he wasn't sharing the room; he had more privacy, I suppose, and maybe it made him feel less sick or more like he was before he was diagnosed or more like he was before he was hospitalised...

5

Home was considered to be an environment that enabled people freedom of expression and allowed a sense of identity. A family friend of a woman who died at home highlighted the significance of friends and family being able to visit the young woman in her own home:

The little boys were able to be there because they could run around and make a noise without disturbing any other patients and intruding on any other people in that hospital situation.

6

Another quality that home offered was maintaining a sense of normality:

For sixty-one years he'd never lived anywhere else apart from boarding school and he just loved it so much.

20

The following example shows how people regarded involvement in everyday activities as important for maintaining a sense of normality.

It's just part of life. It just went on. The kids came down from [interstate] about two weeks before she died and they'd be playing and mucking around and watching; you know, she couldn't watch television much but they'd be watching telly in the other room and as she said, her life was still going on. It kept things to a normality, if there was a normality, and she was involved as much as she could right to the very end. The kids would do a picture and take it in and show her and she'd open her eyes and say, 'That's lovely, dear', and, like, my sister's sixtieth birthday was two days before Mum died and we baked a cake and we had a party and sat Mum up on the couch and had pictures of Mum with a big piece of chocolate cake... [she] had some wine and proceeded to tell all the grandchildren that were there how much she loved them, each individually and why, you know. It was lovely. 8

Providing a sense of familiarity, security and privacy were also cited as important reasons for dying at home. The following participant described what home offered:

At home, she had all her, all the, what can I say? Well... the familiar surroundings of home. That's what she wanted and her family could come in at any time ... She and [the little dog] were very close, very, very fond of each other and I used to take [the little dog] up to her bedroom. She used to cuddle [the little dog] ... [the dog] was very, very special to her. 9

Remaining at home also enabled people to exercise some control, as highlighted by the following comment from one participant:

He really wanted to be in control of what was happening to him. 1

One participant understood that home not only enabled more control over how they managed the dying process but also throughout the time of death and into the post-death period. Having time to do things in a relaxed manner was considered important.

I think that we had more ownership of [her] once she had died ... I don't think there is a rush to leave a hospital or a palliative care situation but I think, given the atmosphere it's in, like the finality; now you move out of here and especially given ten-thirty at night; I'm sure we wouldn't have felt comfortable staying there with [her] until eleven thirty the next day. I think they may have had to have had [the funeral director] in sooner and do all of those things; whereas there was no rush. There was the ease of it, and I understand it's not always possible for that to happen but in this case, it was certainly a very beautiful way for her to be able to go, with her own things around her. 6

Another participant explained how home is a 'place you love' offering 'security and peace':

I don't think you would feel as vulnerable. If you're in your cocoon, so to speak, you've got to feel more settled. If you put people in a sterile strange environment with people they don't know, you'd have to be frightened... You're not thrust into a situation that you don't know. I think you're far more relaxed at home. If you don't feel well enough, well then, you just sort of lie there and do whatever you want. You've got the people that care about you, around you. It's not as if they're just coming in for an hour or two a day. You're in the midst of it and you're still within the family unit, not removed from that prior to dying and I think that's got to give you a far, far better sense of security and peace 21

More than half the participants in this study expressed the importance of being able to have close proximity with the person who was dying. The site of the home was regarded as more able to offer this than an institutional setting:

It allowed us to be together, as close as we wanted, as long as we wanted. There was no, sort of, having to go home or having to come back for visiting, 'cos going backwards and forwards to hospital in the ten days that he was there, I found to be extremely tiring, wearing. I found that far more emotionally challenging than having him at home and knowing that he was in the bedroom and I was around and able to be called at anytime, and sort of have things, the television was there if he wanted to watch it, there was music there that he could have on. 16

The following comment offered by one participant conveys the ease of being able to observe her daughter at any hour of the day or night in the site of the home. This particular episode refers to the morning of the day that the participant's daughter died:

I remember getting up on that very last morning. It was cold, although it was November. Going in about four o'clock I think, and sitting beside her bed and she was dozing and I don't know that we talked very much. I used to wake and go in and have a look at her and go back to bed and I know that morning in particular I got up and sat there early. It wasn't even daylight. 12

Travelling backwards and forwards from hospital was cited as an 'inconvenience' for some participants in terms of time, energy and expenditure. The parents of two infant daughters who died at home explained that they 'wanted to be there all the time'. In the privacy of their own home, these parents said that they could 'be ourselves.'

Staying Close

Enabling someone to die at home involved a deep connection with another person, which was instrumental in helping people to overcome the challenges they faced. Although participants cited witnessing their significant other person suffering pain as being one of their most distressing experiences, people still made a commitment to be with the person throughout these times. The commitment to the relationship assisted people to stay and companion their close other person despite experiencing exhaustion, stress, long, extended periods of time away from other relationships, criticism and interference. Participants understood the toll these different aspects had upon their wellbeing but they were certain that they would not have chosen to walk away.

Caring and keeping watch over a significant other person would usually result in extreme fatigue. The following examples illustrate how people experienced the weariness associated with remaining with another person, commencing with a participant whose husband was dying:

You had to function. You were the nurse; you were the mother; you were the 'be nice to everyone' that came through the door and you were exhausted and so you were on automatic pilot and you functioned. I don't think you felt, really; I don't think I felt along the way but I was very protective about [my husband] not having to lose his dignity in a hospital and so nothing mattered. I just had to achieve a dignified death with as much comfort and pain control as needed and whatever length, that was my prime purpose of whatever length I had to go to achieve that dignified death and as pain-free as possible is what we and [my friends] as nurses worked towards... 10

Night-times were commonly remembered as being very difficult for participants:

It was all very distressing... as the weeks progressed [my husband] just got more and more confused. He couldn't see properly; it was the morphine; it was pretty strong and he was in a lot of pain, so he needed the morphine. And if he tried to get up out of bed I had to sleep and hold him all night, 'cos he'd wander off and then you didn't know where he was and his voice was so weak, you couldn't hear him. You know, a couple of nights you could hear, 'Help, help,' from the front room or wherever he'd got himself and he didn't know where he was. 2

They were very long nights; very long nights and not a lot of sleep. You'd go to sleep for a few hours and wake up and it was like you were on high alert all the time. It was like I'd go to bed and I'd just fall into this sleep but then I'd only sleep for a couple of hours and I'd wake up again and the first thought that would come into your mind is, 'What's happening?' and you'd be straight out there again. 16

He was really funny because he'd wake in the night and he'd be in pain and I'd get up and have a cup of tea at two or three o'clock in the morning. This went on every night. You'd go to bed at whatever and you'd be up at midnight; you'd be up at two; you'd be up at four and so forth. A couple of times he said, 'Why don't you put me into [hospital]? Why don't you put me down there?' I said, 'No, I'm not going to send you down there. Do you want to go down there?' And he said, 'No, I want to stay here'. I said, 'Right, well that's all there is to it' ... the last three months were the hardest. The last three months were terrible and two months of that I was still working full time and I was probably getting roughly two hours sleep a night and I don't know. I don't know how you do it. I think you just probably shut down that part of you that thinks you're fatigued or whatever and continue on with it. 21

The following two quotations demonstrate how others made observations of people who attend to the significant other person, affirming that caring for someone dying is an exhausting activity:

But the kids used to say to me after, 'We didn't think you'd claw your way back again'. They thought I got down so far. It got to a stage where I'd think, 'Give me the strength to get through today. How am I going to do it?' I just was getting so physically exhausted and mentally strained. 14

Doctor [-] had been and said I needed sleeping tablets. I suppose I looked pretty terrible by this stage and I said, 'No, [our daughter] might need me in the middle of the night. If I can't go to sleep, I'll just lay there and have a rest'. Even if she turned over in bed, I'd hear her. You do get this way that you tune into their wave length and you do hear them... You sort of really burn the candle at both ends. I know there in the last weeks, you don't eat properly, you don't sleep. I didn't eat properly for months. The doctor went crook at me. He said, '[-] are you eating properly?' 'Yes,' I said, 'I'm living on caffeine and nicotine. I'm doing well'. It is hard. It's a very stressful time for everybody. 19

One participant remembered how exhausting the task of caring for her husband was, describing her regret for being irritable but also acknowledging her resolve to enable her husband to die at home:

In the last couple of weeks, I suppose, that's the other thing I feel sad about, I got grumpy with him because I was up all night and he was adamant that I slept in the bed with him; cuddled up. I've had friends who slept in a stretcher beside the bed but no, wouldn't have any of that, so, that was alright. I remember being a bit weepy a couple of times saying 'If you don't let me go to sleep, I can't keep you at home'. I was staggering around and I've still got a bad sleeping pattern now. I knew I was going to keep him there but I did get crabby a few times. 20

People recognised the stress they experienced. One participant explained how she began to suffer physical symptoms:

I had this real tightness in my chest and then my sister said [to the doctor], 'You'd better check my sister out while you're here; make sure she's okay; she's got all these pains in her chest', which he said he thought in hindsight was probably just stress. I was starting to feel really stressed about it, and so he said, 'Do you feel really uptight about it?' and I said, 'I do. I feel mean for saying this but I just want it to be over. I feel it's time and I just feel it's time for him to let go,' and so I was really struggling with that ... and he asked me why, and the other thing, the main reason I felt like that too was because I was starting to question whether we'd done the right thing letting him die at home and the reason why I was, because he had bed sores because we had no pressure mattresses or air mattresses or anything, so he had pressure sores and when the nurses came in that night to check on him, when they went to move him, he would cry.

7

The duration in which people cared for their significant other person at home before the death varied from a few weeks to more than two decades. Committing to the relationship often meant that people had to surrender other interests and sacrifice other relationships, including participating in the workplace:

... so I cared for him for eight years. Yes. It was a long time. First few years weren't so bad because he wasn't too bad. He could get around a little bit you know, but then as the years went on, and then the nurses used to come twice a week to start with, and then it got that they came every week day.

14

We had no social life for probably twenty years. I had no independent life other than work and care for most of those years.

15

Staying with the person sometimes meant having to share and negotiate the relationship with others, who could sometimes express disapproval or criticism of the care being given. A quarter of the participants in this study explained that they were either advised by others not to have the death of their significant other person at home or were criticised for their efforts. As indicated in the following examples, criticism and advice was expressed by family members, medical personnel, friends and work colleagues:

My son said, 'Oh Mum, you shouldn't let Dad die at home. It's going to make you hate this house for ever'.

2

The GP became quite offensive in so far he suggested we couldn't do it at home and that we, being my friend and myself; and he throwing that challenge out really upset the two of us, so we were more determined to achieve the ultimate... 10

A friend said to me, '[-], you're going to have to face the fact that you're going to have to put him in a nursing home,' and I said, 'I'll cross that bridge when I come to it'. 15

A colleague from [work] phoned me because I used to check my messages occasionally and I can remember sitting out on the garden seat in Mum and Dad's backyard and talking to him on the phone and he asked me why we didn't have Dad in hospital. 'Why are you doing this? Why haven't you got him in hospital? He'd be better looked after in there'. I was just stunned because it was probably five days after virtually no sleep. I just could not believe that someone would say that to you. He obviously had no understanding. I've thought he had no compassion or a lack of compassion. That has probably changed my feelings about that person from that day. 16

One participant explained how her grandson and son lived with her and her husband as her husband was dying. In describing her husband's relationship with his grandson, she said that 'they just adored each other'. Despite this relationship being built on principles of love, honesty and transparency, some people criticised her for having their grandson involved:

After he died, you know, I have had a few people, no, just a couple of people say, 'Oh, you shouldn't have had him involved that much'. 23

For some families, the criticism between different family members caused tension:

I didn't have much support from family. I felt I had a bit of a battle there, you know, with my brother. I understand now but at the time, I found that very difficult to cope with. And he has since apologised to me, because he was really putting me down and saying that I was making Mum worse by molycoddling her, instead of letting her get on with life, sort of thing, because he hadn't accepted that she was going to die. So that was hard, that was hard. 4

The final aspect of the experience of staying close is the interference of others. For three participants, the pastoral support offered throughout end of life was 'intrusive', a 'nuisance', and one participant felt 'slightly disturbed' by a priest's insensitive behaviour. In the following example, a participant recalls the officious meddling of a pastor:

[My husband] had done some tiling for this guy who was a pastor of one of the not just ordinary mainstream churches, I don't know if it's Pentecostal or what it was. But [he] had just been fairly friendly and they'd talked a lot about one thing or another and I can't even remember how he came up on the scene, but somewhere along the line he must have heard that [my husband] was sick and decided to come and got heavily into healing and that sort of thing with [my husband] and it almost became a nuisance... very much an intrusion, even to the extent that towards the end, he was saying to [my husband], 'I'll help your wife sort everything out, finances, all the rest of it', and [my husband] couldn't even speak at that stage. You could see the agitation rise in him. He was desperate to tell me 'No!' I could feel it coming from him and when this guy left, I leant down to him and said not to worry and I knew very well that only myself and my solicitor and the accountant, who he trusted both of them, and so I was able to comfort him. So this guy was very intrusive... a nuisance. 2

People described their reason for staying with their close other person as one of 'duty' and 'love' and 'giving back':

And there was never, ever, ever any question of walking away from it! I just did it because, well the die is cast and you deal with it, don't you? 14

You do it because it's your duty for one thing and you loved him for the second thing. You don't just walk away when the going gets tough; well, I don't think you do. So, it was hard work; very hard work. 15

A lot of people said to me when I decided to keep Dad at home, 'You're silly. You shouldn't do it'. And I said, 'Well, why shouldn't I do it?' 'Oh well, you know, you've got your life to live'. I said, 'Yes, I might have my life to live but you stop and think about it. All of us, when we're born, who looks after us until we are old enough to be independent and to do what we have to do with our life? Who is there for us and if you can't give back a little, what use are you?' 21

Concluding Comments to the Chapter

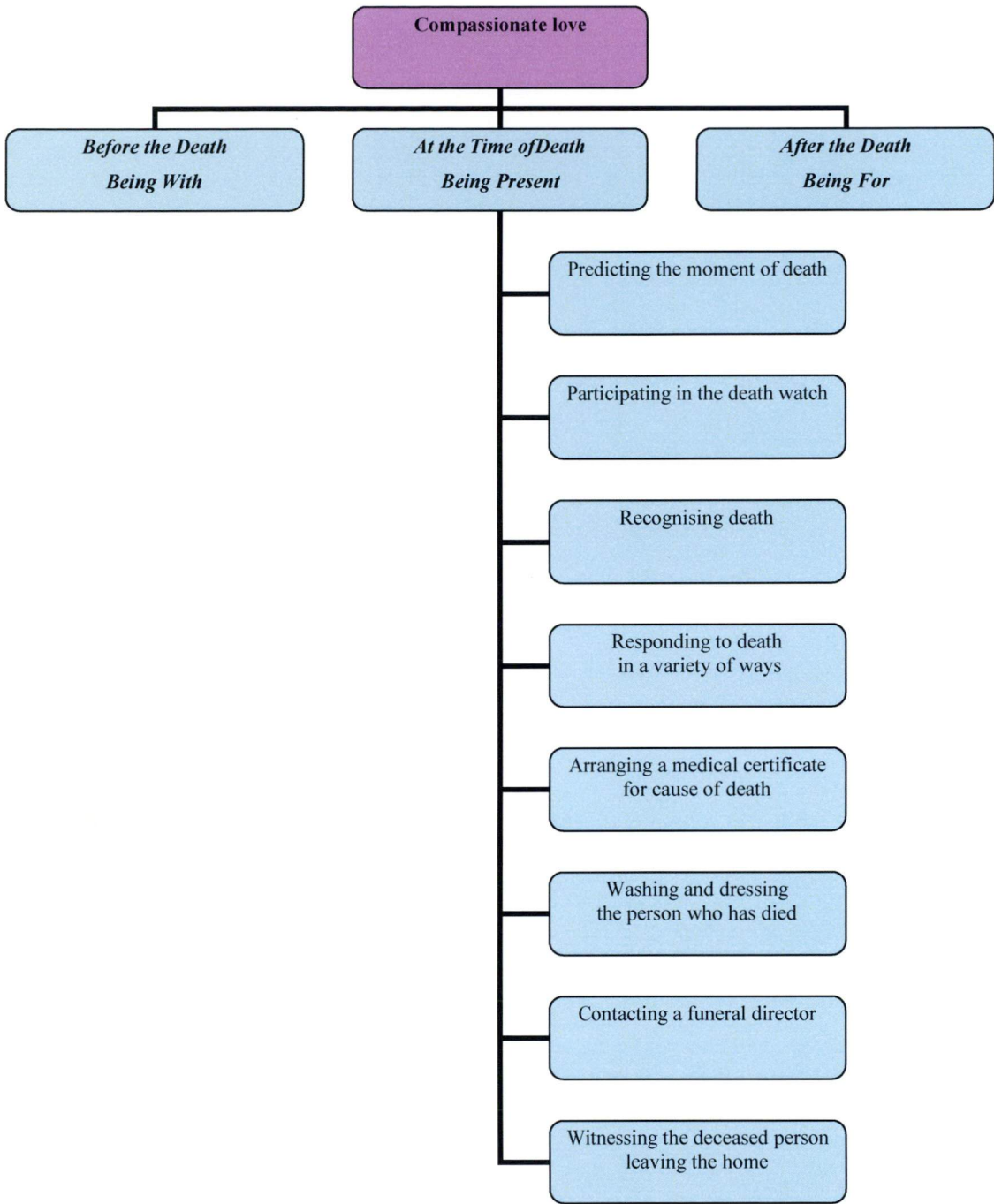
The diagnosis of a life limiting illness heralds the news of an impending death and brings with it a cascade of changes, not only in the life of the person who is dying but also in the lives of the people who support the person to die at home. People's experiences throughout this period are embodied within the context of a close relationship, which is characterised with attentiveness and a commitment to care. Experiences of exhaustion and uncertainty are common amongst participants. The time leading on from this period is known as 'The Time of Death' in which the experiential accounts are identified by the core theme of 'Being Present'.

Chapter 8: At the Time of Death — Being Present

Introduction to the Chapter

The temporal period known as ‘The Time of Death’ signifies a transition from life to death and depicts experiences of ‘Being Present’. This section focuses on the period in which people attend, knowing that their significant other person will soon die or has already died. Death may be regarded as a specific moment in time or a prolonged event which precipitates a series of other events. When death does occur, it is confirmed by the absence of vital life signs, although the actual moment of death does not necessarily have to be witnessed. For the purposes of this study, the period ends when the significant other person who has died is removed from the site of the home. The following figure (Figure 3) illustrates participants’ experiential accounts throughout this period.

Figure 3: Participants' Experiences at the Time of Death



Predicting the Moment of Death

Because medical and pharmaceutical technologies have the capacity to hinder death, knowing when the moment will transpire becomes increasingly difficult to predict. Dying with a life limiting illness is progressive and even without intervention the actual moment of death can remain elusive. It is possible, therefore, that the elusiveness of predicting the moment of death adds to its mystery. Knowing the moment when a person would die was important for all participants but actually knowing when proved to be a slippery ideal. This was difficult particularly when participants had experienced situations where they expected their significant other person to die, only to find that they had recovered through medical interventions:

But I just sort of knew that it was going to happen but I didn't know when. 13

I sort of gathered things were imminent, and then when he passed into a coma on the Saturday, I don't quite know when it was, I knew things were pretty close and in the morning, he was still alive, in the morning the lady who had sat through the night said she was surprised that he was still hanging on. 3

Three aspects of predicting the moment of death were evident in this study. The first two include trying to get an answer and 'knowing', and sometimes these dimensions overlapped. The third aspect involved waiting for someone. The matter of knowing when death would transpire was given considerable thought and discussed with other people, in particular nurses and doctors, as a means to gauge when the event would occur:

This last morning, on the Monday morning, I said to the girl, 'How do you know when they are going to die?' and she was very specific about it. She said, 'Oh, the breathing will change'. Now this is the actual moment of death that she was talking about. I was still looking at perhaps a few more weeks. 14

One participant explained that their doctor was unwilling to identify a day when her daughter would die. His practice wisdom enabled him to know that the moment of death was indefinable:

When I asked him, he said, 'I couldn't tell you two days, or three days because if a patient asks me, I couldn't tell them two days or three days because on that second day you'd be saying, "well today's the day", but it mightn't happen'. 12

One participant explained how the medical staff did not recognise that her husband was in the terminal phase of his dying, despite his unresponsiveness, his changed respirations and his inability to talk and walk without assistance. Discharging himself from hospital with the doctor's belief that he was not in 'imminent danger of dying', this man died at home that very same night. His wife recalls:

We put him into bed and he was rasping. He was okay and we didn't take too much notice and we covered him over and I went to bed probably two, or three hours later and he was just the same as we had put him there. He was lying there. He was wheezy, which he never was, but it didn't really concern me because I thought he had seriously damaged himself when he had fallen out of his bed and I thought, 'I reckon his lungs are clogging up with something. He's damaged a blood vessel or something'. That was alright. I went to bed. I listened to him breathing like I always did. I woke up two hours later and he was dead. 15

Another participant explained that her experience with the elusive nature of death and the prognostic challenge confronting doctors and nurses, informed her that time frames are merely guides and cannot provide a precise indication of what life remains:

We didn't think there was going to be very much time, but in effect it was ten days. People say to me now, at different times, 'Oh the doctor said this,' and I always say 'Don't take any notice of time frames because they mean nothing. They are just a guide'. 16

Despite the evidence indicating that the moment of death is difficult for most people to predict, some experiences of people in this study demonstrate a disruption to the data. Several participants spoke of knowing that death would occur within a matter of hours, as demonstrated in the following comment:

We'd been told two days before, 'Oh look, she's so strong. She's hanging on. It mightn't happen for two or three weeks,' but I just knew. 24

Three participants in the study spoke of how they intuitively knew that the death of their significant other person was about to occur within a matter of minutes, despite not being in close physical proximity to their significant other person:

My great friend came up on the way to church with some soup. She just gave [my husband] a kiss, virtually said goodbye and I went out to the car with her to see her off and we were yattering away as you do. I knew the other two were with him. I wasn't too worried. I suddenly said, 'I think I'd better go and you'd better go'. Went inside, sat down and then he died. 20

The other participants who explained how their significant other people knew that their deaths were imminent, demonstrate how diverse the pathway is to dying; some people slipped into a state of unconsciousness for several days before they died and others maintained the capacity to talk in the moments before they took their last breath. In one instance, a participant explained how her father's prediction that he would die the following day proved correct:

I said to him this particular day — he had two real good old mates and one that he had gone right through school with and the other one he'd played cricket and everything with, and they used to come every day and this particular day, old [-] came; it was a Friday and [-] came and he said, 'Can I give him a beer?' and I said, 'No, you can't give him a beer because I've just given him morphine. You can have a beer with him tomorrow,' and Dad said, 'Too bloody late tomorrow'. I said, 'What do you mean?' He said, 'I won't be here tomorrow. I said, 'Well that's nice because we're pulling the kitchen out tomorrow. Don't do this to me Dad. I haven't got time'. Anyway, [-] went off and the neighbours came down and saw him as they did every couple of days and his sister was coming from [a place] the next day, the Saturday. He said to me, it was tea time and we were having tea and he said, 'You'd better ring [my sister] up,' and I said, 'What for? She'll be here in the morning'. He said, 'Oh, tell her not to come. I'm not going to be here'. I said, 'I can't ring her up and tell her that. How do I tell her that?' He said, 'Just tell her not to come because I won't be here'. 21

Four participants described how the person who was dying waited for contact from someone significant in their lives before they died, suggesting that these people had some control in the timing of their own deaths. The following excerpt shows how one of these participants interpreted the timing of her husband's death:

I felt he was hanging on for some reason and he has a sister in [-] and there is a ten year difference, and her father left when she was born, so my husband was basically the father figure for her and so they were extremely close and I always felt that he needed to hear from her, so I rang her and said '[My husband] is in a coma, he won't be able to respond, but I believe that he can hear and I think he needs to know you care'. So she talked to him. My son's partner had also sent a letter that hadn't arrived and I knew she wanted to say something to him, so I rang her and she had a talk and about, oh, within the hour, he died. I just think he needed that permission from his sister to know that she was going to be alright. 3

The findings from this study show that death becomes a mysterious event when its timing is so arbitrary. Although the process of dying may be identified, the actual timing of the moment of death remains a unique experience for each individual.

Participating in the Death Watch

Participating in the death watch reveals three key aspects: the act of gathering to witness the event; connecting with the person dying; and the feelings and thoughts associated with the experience. Just over three-quarters of participants explained that witnessing their significant other person's health deteriorate caused them considerable anguish and distress. Participants spoke of seeing their significant other person in terms of being 'restless', 'irritable', 'uncomfortable', 'in a pretty bad state' and 'delirious'. Strong visual images of seeing 'ulcers forming on various parts of his body', and 'bed sores' were also mentioned. Other participants recalled 'death-rattles', 'Cheyne-Stokes breathing' and 'really bad breath'. Symptoms of pain, drowsiness, fatigue, cold extremities, unresponsiveness, irregular or shallow breathing, delirium, restlessness, increased respiratory secretions, decreased appetite and decreased thirst, loss of control of bowel or bladder, and the breaking down of skin were described by participants. These symptoms all indicated the process of dying but knowing when the actual event of death would occur was difficult because some of these symptoms proved to be relentlessly ongoing.

The first aspect of participating in the death watch involves the act of gathering to witness the event. Several features become evident: the importance of witnessing the

moment; those in attendance, and those who didn't attend. For all those who gathered at the death watch, being present was spoken of as being an imperative. Being present at the time of death was often expressed as a worry that participants would miss the moment. People feared that their significant other person would die alone, without their companionship. One participant described how being in the presence of her father at the time of his death was crucial in light of her sorrow associated with her brother's sudden demise in hospital:

We spent from Saturday through until the Wednesday, and he was just dying so slowly, but having said that it was really hard because there were lots of precious moments that we had as a family, because the three of us being there and my Mum, we basically just took it in turns laying on the bed and sitting around the bed talking and we slept in there at night with him and we would swap over and we would do three hour shifts and swap over and someone would have a lay down and the other would lay down with him and we talked about so much stuff in the day and funny things that happened and stories with my brother and him and, yeah, we had lots of time and lots of people who were calling in, like Dad's sister, and she would sit and we would just sit around and talk. So we had lots of time to do all of that stuff which was really important, but by the Wednesday morning, it was getting to be really, I really started to struggle with it. I think it was because we had gone, Saturday night, Sunday night, Monday night, Tuesday night; we weren't getting a lot of sleep. I think in hindsight that was a lot of it, because you're tired and you don't want to be and because we were so determined to be there when he died and the main reason in hindsight we felt like that was because my brother had died extremely quickly in the accident and emergency department and none of us had an opportunity to say goodbye to him and he had been sick for a very long time as well, but then had died really suddenly.

7

When people were aware of impending death, the process of waiting and watching began. Feeling for a pulse and listening to heartbeats were activities that most participants described as strategies to ascertain when the death of their significant other person would occur. Another strategy people used to ascertain when the time of death might occur was a perceived change in breathing. The following two excerpts demonstrate the attentiveness of people at end of life. It is evident that people's perception was heightened at this particular time and that they were anticipating their significant other person's transition out of life:

You could feel the heart; it would flutter and then miss a few and then it would come back and, like, over a period of about an hour or so, I knew it was only, like, a very short time.

4

His breathing was really rough and he'd take a really deep breath and then not breathe for fifty seconds and of course each time he didn't breathe, my heart stopped, thinking 'Is this it? Is this it?' And then he'd start to breathe again. 17

The next aspect of gathering to witness the event involves those who attended. Only certain people and animals who had a close connection or a supportive role to play attended the death watch, thereby highlighting the privileged and private space embodied in the death scene. People who did gather at the scene of death were often described as having a 'loving' and 'caring' relationship with the person who was dying, supporting the claim that those in attendance were a select group of people:

Yes, we had a room full. It was like opening night at the theatre but it was just people that loved him... He went off with everybody; how he would have loved it; everybody just chatting away up over him and he would have just loved that, you know. He knew that he was loved to death [laugh]. That was a bit of a bad choice of words, but he was loved to death. 23

Some participants remembered how their companion animals gathered at the death scene and how they became integral in keeping the person company:

His little body was so frail and to see him there on the bed with his cat beside him would break the strongest heart. The day went on and everyone present sensed the feeling of the end being near. 27

Just before he died, we'd got a little dog and [my husband] was very strict about the dog in the bedroom. She was never allowed, and so she would never cross the threshold of the bedroom door. She'd sit with her little feet on the edge. She was sitting out in the hallway and just before he died, she came in, which she never, never would have done, and just sat under the bed, very quietly. 7

People explained that having someone to speak to for reassurance, to share information or to be there at the moment helped sustain them throughout the death watch. The following two examples demonstrate this experience:

When he went into the coma, that's when I did ring [a friend], or it was some time after, because he was in the coma for many hours. I suppose I panicked a little bit and thought 'What do I do when?' like it was inevitable that he was going to die, kind of thing, what happens, and I suppose [my friend] calmed me down and said 'It's alright, just take your time and ring me back, just take your time, there's no big rush, kind of thing,' because I thought I had to deal with things right now and here and [my partner] was there and I had people who would ring, like my cousin

and [name] who helped arrange; and the nurse; although she wasn't there initially, she came later but I'd phoned the Doctor; so all those people had obviously been there in situations where people had died in the home. 5

In the other example, a mother spoke of how her son gave her the strength to stay grounded when she was watching over her mother throughout the final hours of her life:

My then twenty-three year old who had never had anything to do with illness or dying; he just sat in a chair at the end of the bed and he had one of her feet and he was massaging and playing with her feet and he wasn't teary or anything. Every time I felt like I was kind of really, really losing the plot, I'd just look up and he'd just give me this wise, loving smile and the strength I drew from it was amazing. 24

The third aspect of gathering at the death watch involves those who did not attend. More than a quarter of the participants explained that at least one other person who had a close relationship with the person dying did not become involved with the care, nor did they attend the time of death. Two participants described the contrast in their sons' responses, showing how people in the same family can respond to a situation differently:

One of my sons came to visit. It's funny. One son would come to visit; the other one didn't. He couldn't. He came once and that was it. I told him he didn't have to come back anymore because you can't make people; if they're not comfortable with it, that's fine. 16

Well, my youngest son, he'd helped so much with [my husband] when he was ill and was so brilliant with nursing and that side of it; nothing like that bothered him at all; the colostomy bag, nothing like that phased him; whereas [my other son] couldn't bear anything like seeing his Dad going down hill like this. 2

One of these participants also explained how her brother found it difficult to be in the presence of their father dying. Her empathy for her brother's distress is evident in this passage, again demonstrating how participants understand that this endeavour is not an undertaking that can be expected from everyone in the community:

He found it very difficult to deal with the whole, seeing Dad the way he was and doing the hygiene and things like that for him. He was really struggling with it the longer time went on. He came in the beginning because he wanted to help and be there but as the time became longer ... I guess we all started to think, like how long is this going to last? And you got to the stage where you wanted Dad to go because it was just so cruel. Anyway, he left on the Saturday and I feel sorry for

him because it was so hard for him. Plus he felt so guilty because he couldn't be like us. He felt like he was letting us down. 16

Another participant described the absence of her father and brother throughout her mother's end of life:

My Dad was downstairs. He knew she was dying. I'd told him but he didn't want to come up, and my brother, I'd rung him and he wouldn't come around. He just played some music at home; that's how he coped. 4

For one participant and her dying husband, the decision for two of their children not to be present at their father's end of life was made in the weeks prior to his death:

They offered to come before when he was dying and he didn't want it and they didn't really either. They wanted to remember him how he was. He just did not want them to see him how he was, not to remember him like that, so he said no. He didn't want them to see him and they were relieved they didn't have to come either. They made the offer and would have come if he'd wanted them but he said no and I think that's very wise. 20

One participant described how a family member did not attend because he could not understand, despite her continued efforts to portray the reality of her mother's dying.

Trying to tell Grandpa that Mum was so sick and he kept saying, because he's a simple soul, a farmer, not highly educated and he kept saying, 'Just give her a good feed. She'll be right, just give her something to eat'. I said, 'No, she's very, very sick. She's dying,' and he said, 'No.' He wouldn't absorb it because she was strong and intelligent. She'd done all the bills, you know, Mum was, I suppose, the backbone of the whole family, so he wouldn't accept it and even the night she died, the next night, the twenty-four hours after, because we'd been taking turns with her throughout the day because she didn't come down, she wasn't well enough, and she started to ... her breathing was changing and he was getting into his jammies and [my sister] said, 'You'd better go down and get him'. So I went down and said, 'Come on. You need to come up now. Mum's dying,' and he said, 'Oh, I just need to get...' and I said, 'Now. You've got to come now. If you want to be with her, you've got to come now,' and even then, he couldn't get it. It was too big for him. 8

In the final example, a participant explained how she made attempts to encourage her niece and nephew to spend more time with their dying mother. The request from her

brother-in-law to alert him of his wife's transition from life to death offers insight to the responsibility delegated to her and of other people's trust in her dependability. This quotation also speaks of being alone despite having the close physical proximity of others in the household:

I used to say to her daughter and her son, the older two who weren't coping very well, 'Why don't you go and spend some time with Mum?' 'No, no, you're doing it. We're happy for you to be there'. They were there. They would come in and give her a cuddle and a kiss or whatever but most of the time they vamoosed. It was easier for them, I think, not to face it... she had all that muck coming out of her mouth at the time and I kept cleaning it up. Everybody was sitting around and I still remember wishing some of them would go. Most of the ones that weren't related did go downstairs but even the husband sat downstairs watching television with his mates, close friends who were there with him and his son, and he just said to me, 'Will you come and get me at the time?' He couldn't sit there and he couldn't cope with the noise of the horrible stuff coming out of her mouth and so she took a long time; well, I think she took a long time to die. 26

The findings in this study suggest that the reasons why people do not participate in the death watch are diverse. Family estrangement, dementia, fear, an aversion to physical deterioration and a desire to remember the dying person in a particular way are reasons given as to why some members of a care network did not participate in the death watch.

The second aspect of participating in the death watch involves connecting. Participating in this event enabled people to connect physically and emotionally with the person who was dying. Being present offered people the opportunity to communicate through touching and speaking. The first example of communicating feelings is spoken by a man whose wife was dying:

I remember the community nurse kept saying to me, 'Keep talking to her, keep talking to her. She'll hear you'. So I did and the last thing I remember saying to her, I leant over and whispered in her ear, 'I love you,' and prior to that she couldn't even lift her arm off the bed but she grabbed me behind the neck and kissed me with tremendous energy and told me how much she loved me. She said, 'I do, I do, I do, I do'. 25

The next example of connecting intimately with the person who was dying involves two parents and their child:

At about 3.00pm that Tuesday afternoon [our son] asked his father to pick him up and take him to our bed, and asked us to lie with him. [My husband] gently picked him up and carried him to our room and I knew then that only hours were left. As we lay there beside him our emotions were very hard to control. My parents were informed of what was happening and arrived shortly afterwards to be with their beloved grandson for the last time. The tension in the house was obvious as everyone tried to prepare themselves for what was ahead. As I lay there with [our son], whispering in his ear of our love and feelings for him, the tears came without shame and although at one stage there were at least fourteen people in the house, it felt very empty.

27

A third of the participants said how being in the presence of the person who was dying enabled the exchange of love as demonstrated in the following examples:

As her breathing was slowing and stopping we were all sort of saying, 'We love you'. We were yelling out, 'We love you Mum. We love you'.

8

I didn't know what to do. He was perspiry and clammy so I reached over to the dresser and I got a towel and wiped him off and then my heart started to beat. I mean, I knew, just somehow, I knew that was it and I thought, 'What am I going to do?' So, I started to sing to him and we had for our wedding song, the [-] song '[-]' and I started to sing it. He sort of opened his eyes and looked at me and his breathing just calmed right down, like normal and I thought, 'My God, this is amazing'. I mean the whole time I was thinking, 'What do I do? What do I do?' He just sort of looked at me, and had this far-away look in his eyes, and I realised he was focusing in and out. I sat down next to the bed and I held his hand and I told him all the things I wanted him to know. He looked over at me and said, 'I love you,' and then he died.

17

She waited for [-] to say goodbye and she told us how much she loved us. She said, 'It's not the quantity of your life, Mum, it's the quality and the only thing I've ever known is love. Some people never know love'.

19

When participants believed that death was imminent and they did not have a large network of people available for the death watch, they arranged to stay with the person who was dying throughout the night. Sleeping in the same room or in the same bed with the person were strategies used by the participants to remain alert and sustain the vigil. In the following example, a daughter explained how she altered her sleeping arrangements because she sensed her mother's impending death:

I just felt that night, I said to my sister, 'I just want to be in the room with Mum' for some reason, so I just pulled the little mattress in and slept on the floor and I woke up at some stage during the night and I could hear her, breathing, whatever

they call it, gurgling, but it was kind of consistent so I waited awhile and I let my sister have a good sleep and I awoke her early in the morning and she was naturally very upset and I just felt it was the day. 24

In the next example, a participant describes how she negotiated the activity of sleeping, keeping constant physical contact with her mother throughout the night:

Because I was worried she would die in the night when I was asleep and I really didn't want that and I used to sleep — I'm going to cry now — with my hand on her feet. Amazing isn't it, after all this time but that was a very personal thing. I don't think I've ever told anyone that, so I was literally an extension of her body. 4

One participant explained that she was asked to provide support but was mindful of not intruding upon the family's private space:

I suppose around half past seven, eight o'clock when it was dark, it was just a very ... I don't know, it was just a really lovely atmosphere in the room; it was peaceful and more people arrived. Lots of [her] friends came; they'd finished work; they called in and said their goodbyes to [her]; people just sort of came and went. I tended to stay in the background a little bit; went outside; played with the boys; I was very much aware that I wasn't intruding, whilst I was there to support [her mother and father] and the family, but I was also very much aware that it was a very private time for them and at one stage I spoke with [her mother and father] and said when the time appeared not to be too far off, did they want some, just the two of them to have some time, which they did and then [-], [her] brother, he had some time with [her] and during that time, they didn't just sit at the bedside; they were laid up on the bed with [her] and cuddled with her, so they had that private time which was really nice. 6

Several participants explained how children attended the death watch. One participant explained how her young grandson played a crucial role throughout her husbands' dying:

[My husband] adored that little boy ... and the only time he'd come to, was if he knew [his grandson] was in the room and he'd say, 'Come on mate', and [our grandson] would climb up beside him ... [Our grandson] was there when he died. 23

The final aspect of participating in the death watch involves the thoughts and feelings associated with the experience. Despite being in the company of others, a quarter of the participants in this study described feelings of being alone and detached, using such terms as 'removed from the rest of society', 'in a fog', 'in a dream', 'out of this world',

‘functioning on auto-pilot’, ‘closed in’ and ‘switched off’. One participant explained how the time during the death watch appeared ‘weird’, similar to ‘being in limbo’. A quarter of the participants also spoke of their fears and anxieties facing the moment of their significant other person’s death. One participant witnessed a deathbed image in the hours before her mother’s death, causing her alarm:

But just before, like about, probably a couple of hours before she actually died, it really frightened me. She just sat bolt upright in bed and said ‘Hurry up, come on, quickly’ and I thought, ‘Now I think there is an afterlife and our family are coming to meet her or something’. She could see somebody... It was freaky. It was a freaky experience for me. Like, she sat up so quickly, it was almost like a dead person coming back to life that it really gave me a start!

4

In another instance, a daughter explained how being alone in the house with her dying father fuelled feelings of fear:

It was kind of scary, even though I had been around death, I was quite fearful being alone with him in the house, only because he was sick and I thought, ‘Oh God what if he dies now? You know, what would happen?’ And I realised I still had quite a lot of fear about, not that I expressed it except to my brother who said that, when I arrived he said, ‘Oh God, I’m so pleased you’re here,’ and I said, ‘It’s a lot of work,’ and he said ‘No, it’s really scary. You just feel like you’re on your own with death,’ and I said ‘Oh yeah, I’m here now,’ but I can remember, he said ‘Well now you’re here, I’m leaving for a bit. I’m going to go and have a shower and ring in at work, and check in that things are okay’. He also had young kids. And I said, ‘Okay,’ and I can remember him being gone for about three hours and I rang him on his mobile and I said, ‘Can you come back?’

1

The coexistence of courage and fear are evident in the following excerpt:

I was still afraid and I had never gone through it before ... [the nurse] popped in and she said, ‘I think probably it’s close. He could die anytime. Do you want to send him to the hospice?’ I said, ‘Oh, I don’t know’. I thought only of doing it because I was afraid. I didn’t know what was going to happen. It was really scary to think that he was going to die there. I thought about it for a second and then I said, ‘No.’ So she said, ‘Let me just tell you what could happen’. She was about to leave and she came back in and sat on the lounge and she talked about the breathing and the pause in the breaths and this could happen or that could happen, and told me what to watch for. And then she left and then I went into the bedroom.

17

All participants who witnessed their significant other person experience pain and discomfort explained that they wanted the pain and misery to end, ‘wishing for it to hurry up and be over’. One participant’s plea to God to allow his wife to die is spoken in terms of being ‘a shocking thing to say’, illustrating the depth of anguish experienced from bearing witness to his wife’s suffering:

... but on the second last day before she died, she was in an enormous amount of pain, enormous amount of pain and I just said underneath my breath and a shocking thing to say, but I said, ‘Please God let [my wife] die’. I know it’s not good, but that’s the way it was. She was experiencing a shocking amount of pain.

9

In the next passage, a daughter describes the tender, loving care given to her father following a ‘turbulent’ night when her father was delirious, asking her to kill him:

Yeah, like when Dad was in a coma, we were brushing his hair and stroking him, kissing him, cuddling him and we weren’t aware whether he was aware of it or not, and we were playing music and we were still there. It was just after the turbulent night and the experience that he had had, it was just calm and I felt like I should have changed him; he was wet but the nurse changed him; but he was calm and we didn’t want to disturb him; just to feel loved and all that kind of thing.

5

Several participants spoke about having inadequate pain relief for their significant other person. Access to pain relief was cited as being impossible because supplies in the home had either run out or were inadequate, in addition to healthcare workers denying the person an increased dosage or more medication. One of these participants explained that because her husband’s doctor was uncooperative, she needed to seek assistance from her own doctor:

And the fact of having to watch him suffer; that was the thing that really got me. It really, really did. I can honestly say, we had one doctor ... and he was just awful. He was horrible to him. He just said to him, ‘You can’t have any extra morphine and you can’t have this and you can’t have that,’ and I said, ‘But I can’t have him in pain,’ and he got really sick one night and I rang and he said, ‘Oh I’m not coming out’. I said, ‘Fine,’ so I went to my Doctor and she said, ‘Yes, I’ll help,’ and I said to her then, ‘If it gets to the point where he is totally in pain and all the rest of it, I want you to give me something so I can help him on his way,’ and she said, ‘I can’t advise you on that. I’ll give you what’s necessary at the time’.

15

The need for the pain and suffering to end was common amongst participants. The following example is taken from a daughter's narrative in which she describes her father's end of life and the distress it caused her:

I know when Dad was dying in the last couple of days he was in so much pain, and I was injecting him with morphine and, like, three o'clock in the morning, kind of thing, and he was asking — he was quite delirious and he was calling me 'Mum', like I was his mother and he was asking me to actually kill him. Loss of control of his bodily functions and that kind of stuff; really hard to cope with and he was in so much pain and he was so uncomfortable with his body and he just wanted out. So, yeah, there was just nothing we could do but try and relieve his pain and suffering as best we could. We had a certain amount of morphine but he was quite unaware of who we were and all that kind of stuff and you just wanted it to end, and that was where we were at. 5

Normalising the desire for a person to die is encapsulated in the following quotation from the mother of a young boy:

There was one occasion the day before [our son] died when I considered hastening his death by some means. This thought was only fleeting but at the time was very real. I know that this feeling is something that many people have when someone they love is suffering from severe pain and when death is near. 27

The absence of pain made the experience of watching someone dying less traumatic because it was perceived that the person was not suffering; however, the witnessing of their life diminishing and having no control in averting the inevitable event of death, caused participants anguish:

It was not a pleasant experience, because once again, you can't do anything. That was the frustrating thing. There was nothing I could do. The only consolation I had was that I believe he was unconscious. He wouldn't have known, so for him, he wouldn't have been suffering. 14

Participants described how they eliminated noise and occasionally used soft lights and music to evoke a peaceful atmosphere. In many instances the death scene was imbued with a transcendent quality. People in this study were very aware of how they wanted to negotiate the transition of their significant other person out of this life into death:

So we all camped around the bed and had candles and music and it was all very beautiful. They've got a huge window along from their bed and this huge big elm tree sort of overlooking the bedroom. It was rather gorgeous and it rained for a few days that he was dying. It was beautiful. Mum hung an umbrella on the chest of drawers next to the bed and said, 'I reckon you'll be needing that'. It was very, very gentle. There was always someone with him for those twelve days, but particularly in that last time. We'd leave him to have sleeps before that but in his last few days we were always in there. We used to stay the night and one night he was very wide awake. I think it was two nights before he died and he wanted music and he wanted us to talk to him, so we all camped the night around his bed. It was wonderful. Mum hopped in beside him because she never did leave the bed. She was always there with him.

18

One participant's experience in this study highlights how not all factors involved in the death scene can be controlled:

... his actual moment of passing was not peaceful. I thought it would be. I had staged it so that he would be rested. I was playing sort of ambient music and I was with him ...

11

For this participant, the death scene was described as 'a most horrific, obscene passing':

I had sort of paved the way for something pleasant and then it all just turned around with the two [step-sons]. I mean, they didn't know, of course. They were just as much in shock as I was but they reacted by screaming and fighting and hitting each other and I just wanted to say to them, 'Don't. Please. Just don't bully your father,' because one was saying, 'Get a grip, Dad, get a grip. Pull yourself together,' and [my husband] couldn't speak; he was just putting his hand up to ward them off and I was in two minds. I was very conflicted as to whether to let them because they were his sons and who was I, you know, and they were trying to buck him up as if to say, 'Come back. Come back. Don't leave us. We're in a mess here'. And then he sat up and said, 'What time is it?' and he was very slurred and I thought that was strange because he sort of looked at the clock often. He used to wind this antique clock we had on the wall; and the boys thought that he wanted to go to the toilet and I'd stepped out of the room at that moment, and they had got him up and he was absolutely rigid. You could tell and then he turned around and I'll never forget this and I can talk about it now but at the time I just could not believe, he turned and looked at all of us and said, 'Fuck the lot of you'. And then they took him to the toilet. He collapsed and haemorrhaged everywhere and then they just sort of went off the deep end and took off. So we got him back to the bed and made him tidy and comfortable and they just disappeared. The elder one, the one that gave me all the grief, just wasn't seen for days and the younger one, God bless him, came back later and stayed with me that night.

11

Recognising Death

A quarter of the participants in this study found that it was difficult to ascertain when the moment of death had actually transpired. One participant described the shock and distress in finding her husband collapsed in the hallway. This woman had no one else in the house for support and was not sure whether her husband was dead or alive on account of the noise of his nebuliser making it difficult to ascertain whether or not he was still breathing:

So I said, 'I'm off to bed. If you've settled down, your water's there, your nebuliser's there, ring your bell if you want me'. Off I went to bed and because the next morning was Saturday morning, I sort of woke up and I thought, 'Oh!' I usually always get up at seven o'clock. I thought, 'I'm so tired. I think I'll stay a little bit longer'. I could hear his nebuliser going so I thought, 'He's okay, you know'. So that was alright. I thought, 'I'll stay in until half past seven and then get out of bed'. Gets up, goes down to the doorway and here he was on the floor. Nebuliser mask on. So, of course I didn't know what to do. Really! So, I think I started shaking. My teeth were chattering and I thought, 'Stop this. Stop this'. So I rushed to the phone. Got the ambulance and I explained. I said, 'Look, my husband's collapsed on the floor. Actually I don't think he's breathing. I'm not sure, not being a medical person'. And they said, 'Oh, go in and try and do CPR'. Well, because he'd sort of been sideways on the bed because he had to sit up all night and he fell forward, well, you see, he was sort of on the side of his face. And I couldn't move him. He was over sixteen stone and you can see how big I am. Oh, and well, I'm nearly in tears by then because I couldn't move him, so I went back out and I said, 'Look I can't move him. I don't know what to do'. And they said, 'Look, don't worry. The ambulance is on its way'. 13

When people were present at the moment of death, it was generally the absence of vital signs that heralded to participants that their significant other person had died:

I just held her pulse until it beat no more. 4

... he just took his last breath. When he did, you knew. You didn't wait for him to take another one. You knew. 16

In addition to the lack of vital signs, almost a quarter of participants mentioned a stillness or silence associated with the time of death. This quietness was often in stark contrast to the noise of laboured breathing or the restlessness that heralded impending death:

I sensed the uncanny silence and realised immediately that [our son] was no longer fighting for his breath and that he was dead. 27

Reference was made by participants to the person having left or gone away with a concomitant emptiness or shell-like quality. In the following example one participant describes this experience:

I mean, he wasn't there anymore; you could see he wasn't there... he had gone. 2

People were often amazed at seeing the transition from between being alive to being dead:

You know, there's a total difference from someone being alive and someone being dead. 2

The transcendental nature of death was usually described in terms of a spiritual entity:

It's very different when the spirit has left somebody, isn't it? It wasn't really him. 20

It was like his spirit was sucked out... He was still breathing but he let out his last breath and we were there holding him and kissing him and hugging him and so on and when he went it was just, yeah it was weird; his body was there but he wasn't there ... even though he had been in the coma, it was such a distinct change of state if you like. It was like his shell was there and Dad wasn't there. 5

A quarter of the participants explained how difficult it was, not only to describe what had happened, but also how to make meaning of their experience:

There was only the body left; his spirit, everything else had gone ... It was a really, really strange thing. I don't quite know how to put it into words. When I went down and found him on the floor and I got [my husband] down, and we put him back into bed, I presume it was the last bit of air in his lungs or something, but there was like an 'ahhhh' and you could see every bit of pain and everything was gone from his face and he just looked like he used to look, and I sort of thought, 'You're not here anymore. You're gone. There's just this shell left. That's all there is'. I don't know, I don't know... 21

For some participants, being unable to make sense of the experience promotes the mysterious nature of death. One example, given by a woman in reference to her mother's demise, highlights the transcendental nature of death:

I had this sense, because I was holding her hand, that I was giving the hand to someone else. I didn't know who, but I really think that death is just an altered state of consciousness and she's gone onto the next state of consciousness, as we all will. 4

Almost every participant remembered the timing of death with a measure of precision:

She died in October... Friday morning at ten past seven. 19

Having someone else to witness the moment of death was generally regarded by participants as beneficial. The following two examples are spoken by women who sought confirmation from another support person when they suspected that their husbands had died:

I think I dozed and my dear friend was in the room. I think there was only her and I and she may have even been laying on the other side of the bed beside him or sitting on the chair beside him, but I do know I had dozed and rolled over and he basically took his last breath then and we both looked at each other and recognised that that probably was, but as you'd be understanding, you'd still think, 'Is there another one coming?', but there wasn't. It didn't. 10

We spent a lot of time holding hands and suddenly I said, 'Oh, you've nicked off haven't you?' Oh, when I think about it, I should have said, 'Oh, he's died!' or something, but no. I sort of went with my other hand under his nose and I said to [my friend], 'Quick, no, I think he's here,' and [she] said, 'No, I think he's gone,' and I said, 'Get the mirror from the bathroom,' and we popped that under him and he was. 23

Having someone to confirm that death had happened was expressed as a relief by people. The support of healthcare workers attending the death scene was generally described in favourable terms:

... the nurse was there which was really very good, because she was able to say, 'Yes, he's dead'. 1

I was there when he took his last breath and my husband was there and the nurse. And it was good that she had just rocked up... 5

One participant, however, expressed her relief that a nurse was not present with herself and her husband at the time of their daughter's death:

... she didn't come on the night she actually died and I'm glad she wasn't there. I'm glad it was just the two of us because she might have taken over a bit; who knows? 22

These findings suggest that the way that healthcare workers support people to attend the death scene is more important than the expertise they can offer. Empowering people by means of not asserting authority or by not intruding into a moment when people do not want help or advice may be the crucial element of appropriate support throughout the death watch.

Responding to Death in a Variety of Ways

Participants described a complex interplay of responses to their significant other person's death. While people spoke of the 'shock' to describe the reality of a changed status, no participant refused to acknowledge that their significant other person was dead. Being 'shocked' demonstrated how death imposed a grim reality. Since some people had cared for their significant other person for months, years and in some cases, decades, the death which may have taken a long time to eventuate, was naturally difficult to fully comprehend:

It was just, I guess, in a way, after the initial shock of, 'Oh, my God! He's dead,' and 'I never, ever thought this would happen!' 15

Relief was another common feeling experienced by people in response to their significant other person's death. Relief was expressed in a variety of ways, including laughter:

I mean, when I ran down and saw him, I laughed... Relief, absolute relief. To think that he didn't have to suffer anymore; to think that he didn't have to go through all that pain and struggling to have a breath; the lack of mobility and the loss of dignity and all of that. 21

In addition to the shock and relief, feelings of loss were evident, often described as an 'emptiness'.

... he did suffer so much, in one way it was a relief and then in another way it was just the emptiness. But I thought, well, I'd never want him back because he did suffer those last twelve months. 13

In addition to the shock, relief and emptiness were other expressions of grief, including exhaustion. In four cases, participants spoke of how individuals became irritable or angry with other members of the care network in response to the person's death. One participant made sense of her experience by reflecting upon the context in which the event transpired:

... even though you expect it and you can see that deterioration coming for so long and, you know, I wonder in hindsight whether it's that shock that it's actually happened and that time I wondered also about the mental and the physical tiredness that it takes on you. 7

The second aspect of responding to the death involves what people did. Several features are evident, including: wondering what to do next; taking time; connecting with the person by saying goodbye; caring for others; and attending to formal matters. The question of what needed to be done next was mentioned by several participants, implying a state of transition. One participant described the moment of death as 'a real anti-climax':

Sounds terrible, but it was a flat sort of feeling, like, what do we do now? 1

Several participants explained that they decided not to do anything immediately and chose to go to sleep alongside the person who had just died. This experience is illustrated in the following conversation between the parents of an infant daughter:

Even when she died, we thought, we had a little discussion, 'What do we do? Do we ring a doctor?' ... What's the point?

Yeah, what's the point? The doctor knows she's sick. We'll wait for the morning, so we did... It was in the middle of the night. It was right on midnight; bizarre.

We just put her in the middle of us and lay down and went to sleep. She was our baby and it didn't matter that she was dead, so she just slept in between us. 22

For some people there was no sense of urgency to begin or continue arrangements when a person died. Participants used terms like ‘taking our time’, and ‘no rush’. During that time, participants explained that they made their ‘farewells’, said their ‘goodbyes’ and ‘talked’ to the person who had died.

The period in which the person’s body remained in the home varied. Some people were content to have the person for a couple of hours, whereas others wanted their significant other person to remain with them for several days. Connecting with the person who died was important, providing the opportunity to say goodbye:

I don't remember how long we stayed with her body straight after she died but we kept the body for sixteen hours because, well, it was mainly my decision, I wanted to. Well, I kept going back and crying and grieving and it wasn't until nine o'clock the next morning that I rang up the undertaker and said, well, I'd reached a point where I felt and I checked it out with the other kids that I didn't need her body to be there anymore; just felt like it was time for her body to go... Oh, I think because I felt the need, I suppose for my own and my children's needs; for our grieving process to have the body there ... I just went with my feeling. Just knew that I needed her body to still be there.

25

Giving regard to other people’s needs was another feature of responding to the death, evident in a quarter of participants’ stories. Several participants explained that they did not want to intrude upon other people’s personal encounters with the person who had died:

It was a bit tricky in that we didn't want to tread on each other's toes and we didn't want to interfere with Mum. You don't know what people want and people don't know what they want, necessarily. But we'd pop in and out and if Mum was in there crying and talking to him, well, you'd back off and wait until there was a space.

18

One-fifth of the participants felt an immediate responsibility to care for others who became distressed as a result of informing them of the death, despite trying to grapple with the onslaught of their own emotions. The following two examples demonstrate how participants cared for others in response to the death:

Just after she died, I was a bit incoherent. You know how you go back to your childhood and I was just saying, 'Mum, Mum'. And then I had the kids to comfort too, you know, I had the kids. I knew [my daughter] who doesn't handle things very well, she was downstairs and they were crying and they just wouldn't come into the room, so you were sort of torn between your own grief and their grief...

8

I started immediately worrying about my brother and sister, and my nephews because they went to school a couple of doors down. [My sister] said, 'I should let the boys know! What will I do? I don't think the boys should see her'. And I said, 'Well, give them the opportunity. Let them decide whether they want to or not'. So it was almost like, well, Mum was dead; there is the body and I was worried about all these other people, particularly the boys.

24

Participants in the study also explained that they informed all or some of the following people of the death: palliative care nurses; community nurses; doctors, ambulance officers; pastoral workers; funeral attendants; and other significant people in the deceased person's life. The timing in which this was done varied from within minutes following the death to more than eight hours after the person had died. When contact was undertaken, most people explained that they had at least several people to inform, as shown by the following example:

Someone rang our minister, and some one else rang my brother to ask him to go to my parents and let them know... Other necessary phone calls were made to friends and relatives and finally to the funeral directors.

27

Informing healthcare workers of the person's death was important for some participants who explained that this task was done immediately after the death of their significant other person:

I remember after she died, I felt I needed to tell someone and I rang [the nurse] from palliative care. I said to [her], 'She's died,' and she said, 'Do you want me to come?' and I said, 'No, no, we're all right. Everything's okay'. I just needed to tell her.

8

From the moment she died, I rang our GP to tell him and I think within an hour — no, I've forgotten — a short time, he came up and he pronounced her dead. I then rang the community sisters to tell them that she had died to tell them so that they wouldn't come up the next morning and then I rang the funeral parlour.

9

One participant who contacted a nurse from palliative care after her husband died, found that events transpired with haste and regretted the speed in which arrangements were undertaken:

I suppose it was my fault for phoning up the palliative care nurses because you immediately think 'Oh, I've got to tell someone,' and if I hadn't have phoned them straight away, they wouldn't have come straight away, would they? 2

Arranging a Medical Certificate for Cause of Death

Prior to the removal of the body from the home, a medical certificate for cause of death has to be signed by a doctor or a nominated person to eliminate the possibility of any criminal activity. For the majority of participants, contacting the doctor and organising a medical certificate for cause of death was one of the first tasks that participants undertook. In some cases, the person supporting the participant contacted the doctor. Most participants explained that the doctor responded with kindness as demonstrated by the following two examples. In the first instance, a participant describes how the doctor took time to look at the photographs she had been looking at with her husband before he died:

There was a knock at the door and there was the doctor. It was [the doctor]; he's a lovely man. He came in and of course you see in the movies the doctor come in and put the stethoscope on, and they are very official but I answered the door and said, 'He's gone'. He came in; pulled up a chair. It was just amazing. Sat down next to me, held my hand and put a hand on [my husband's] shoulder and looked at the pictures and just said, 'Let's just talk about [your husband]' ' And we just sat there and chatted and he'd say, 'What about this picture?' It was just really amazing. So kind. 17

In the next example, the parents of a baby described how the doctor arrived with flowers:

... then [the doctor] came.

Yeah, [the doctor] came with a bunch of flowers, laid them beside her and she was lovely.

Did the death certificate.

Yeah, just did the doctor thing that you have to do and she said, 'Do you want to keep her here?' and we said, 'Yes, at our house'. We didn't want to move her. 22

Participants explained how they appreciated their doctor being able to attend the death scene and being able to communicate relevant and reliable information:

I rang [the medical specialist] and he came and signed the death certificate and spoke with [her mother and father] and spoke with me and I asked him did we have to do anything that night and he said 'No, not at all; I've signed the death certificate; everything is okay; you can just ring [the funeral director's] when [her mother and father] are ready and then they will come and do whatever has to be done, but if it's three o'clock in the morning that's fine; if it's not 'til eleven o'clock tomorrow morning, that's fine too; there isn't any hurry to move her out of her bed; just when the family are ready'. 6

The findings from this study demonstrate that participants valued the doctor's ability to be contacted regardless of what time the death occurred, and the offering of reliable and competent assistance imparted with compassion, given in a gentle and unhurried manner. Only two participants described incompetent care by their doctor regarding the medical certificate for cause for death. The following example highlights how one of the doctors forgot to arrange the necessary paperwork:

I rang the doctor and of course, the doctor came then ... I was there organising with the funeral people ... when they got there, they said, 'Where's the doctor's certificate?' and I said, 'What doctor's certificate?' They said, 'You're supposed to have a certificate from the doctor to say that they've been and state that we can take him away.' I said, 'Oh, wonderful! How about I ring the doctor?' So I rang the doctor and they spoke to the doctor and the head bloke from the funeral place said, 'We're not supposed to take him until you've got this certificate'. I said, 'Look, I'll go and get the certificate.' ... I then had to race up to the doctor's, get the certificate and race it back it because otherwise they're not supposed to move the body because I suppose it could be an unnatural death or something if a doctor hasn't been on site. So that wasn't very pleasant. 21

Three other participants in the study explained that their contact with medical personnel precipitated responses which caused a series of unfortunate events. One participant spoke about the involvement of the doctor, ambulance, police and coroner:

When I rang the doctor, his reaction was, 'Oh my God! No!' And I said, 'Yes, I think he is dead,' because I wasn't a 100 per cent certain. I was 99.9 per cent

certain. He said, 'I'll be there'. It was only a matter of minutes and he was there. [The doctor] said to them as they walked in because he came with them and the ambulance man had his little bag, and [the doctor] said, 'You're wasting your time'. They came out and said, 'Well, yes'. That's when the fun and games started because he was a trainee doctor. He was still under supervision so he couldn't sign the death certificate and he rang his superior and she said because [my husband] had been in the hospital and voluntarily discharged himself, the coroner would have to be involved and I just said, 'Coroners are for people who die with mysterious problems. Not someone who has been on death's door or was so weak he couldn't walk.' ... So the next thing, there were two police cars in the yard as well as an ambulance. . 15

Another participant remembered the long wait for the police to arrive and could not understand why this series of events transpired in light of her husband's death being anticipated by all services involved in his care:

Well, I remember ringing the doctor here. I don't know who rang the ambulance people... everybody knew that he was going to die at home: the [-] clinic, doctor, everybody we possibly could have told; and blow me down they wanted the police. I think it was the ambulance; couldn't be 100 per cent sure. That was awful. We hung around and we waited and waited and waited for the police to come from [the town] and it was ridiculous. 20

The third person for whom the police attended the scene of death was clearly bewildered by the need for their involvement:

... in the meantime, the ambulance people arrived. They came in and I said, 'Oh look, I tried because they did suggest I do CPR but I couldn't move him'. And they said, 'Well, it's just as well you didn't try because it would have been too late. And there was nothing you could do'. So then, that was alright. I said, 'Well can we cover him up?' and they said, 'No. Got to wait until the police come'. 'Oh,' I thought, 'My goodness me, what?' You know. I said, 'Whatever's going on? Why the police? I haven't done anything!' Apparently if they find people dead, they've got to get the police. Well anyhow, I had to wait and they'd gone out on a call somewhere. So we're sitting here waiting for them to come. 13

In all three cases where the police attended, participants expressed shock and distress. Police involvement was considered an invasion and an inappropriate intervention for a death which resulted from a protracted life limiting illness. The over-reaction of the police in one participant's experience is demonstrated in the following excerpt:

I actually said to them, 'I didn't know that dying at home was an offence' and the police woman just looked at me and she said, 'What do you mean?' and I said, 'Well, if it wasn't an offence, why are you here?' And she said, 'We are trying to be sensitive,' and I said, 'Well, I'd hate to see you if you weren't'. By then, [my daughter] had rung a couple of my friends and they were starting to arrive and it was six in the morning and it was daylight and the doctor was just wonderful. He paced up and down and reprimanded himself and tried to console me. He was just lovely. He was a really great guy. The ambulance man didn't quite know what to do because he had gone through the [place] where I worked and so he didn't quite know where he fitted in the social pecking order or something, I don't know. He felt like he was still a child and I should have been in control, whereas that wasn't the case at all ... but they kept saying to me, 'Just wait until the coroner office man gets here. He's horrible'. The next thing, in comes the police photographer... I nearly died! And they said, 'Oh [-], this is whatever his name was, and he's the police photographer'. And I said, 'Well, why has he come?' 'Oh, because we'll need evidence,' and I thought, 'Evidence. Right. Fine. Okay.' And you're trying to hold yourself together and all these strangers are descending upon you in droves and none of them sit; they all stand or they all walk. Talk in whispered voices to one another and you're thinking, 'Who is the criminal here? This is just disgusting'. And then she said, 'Now we'd really like for you to make a statement.' ... So I said, 'Well, what do I have to say?' and [the police woman] said, 'Tell us what happened'. 'Other than he went to bed last night and he didn't wake up, what else do you want to know?' 'Oh, we'd like a full and detailed account of events leading up'. And I said, 'When do I start?' 'Well,' she said, 'at the beginning'. And I said, 'Thirty-seven years ago. I can't remember that far back' and she wasn't amused. 'Well,' I said, 'I could start at the beginning of the holidays if you like. That was last Friday'. 'Alright,' she said, 'if that's where you think it starts'. 'Well, I don't know where else to start. And you're not being all that helpful. If you want to know what happened yesterday, I'll tell you about yesterday but yesterday was affected by the day before and that was affected by the day before that, so if I start at the beginning of the holidays, which gives you ten days, that should be enough'. 'Yes', she said, 'Alright,' and I sat there. I'd talk and she'd write and I'd talk and she'd write and I'd talk and she'd write. When we got to the end, I said, 'Is that what you wanted?' And she said, 'Yes'. And I said, 'Well, you don't sound very convincing,' and she said, 'Well, we usually get about a page full and I've got seven pages'. 'Well, you didn't tell me you wanted less. You didn't tell me you wanted more. I'm finding this really stressful and really difficult and it seems to me that no matter what I do, it's wrong'. And she said, 'Well, just wait for the coroner man to come.' ... I was just thinking, 'Oh my God!' Anyway, the coroner man arrived in his discreet little maroon station wagon and I thought, 'Okay. Brace yourself'. I was on about the fifteenth cup of coffee by now and he came in and introduced himself and shook me by the hand and offered his sympathy, and he was really the most pleasant of the whole lot.

15

The three participants for whom the police attended the death of their husbands lived in different councils of Tasmania. Two of these people lived in a rural community and one

person lived in a suburban area. None of these people had been previously advised that police involvement might eventuate. For all of these participants, police involvement was a disturbing and inappropriate outcome. This finding highlights how a person's death can evolve in unanticipated ways as a result of the ambulance service responding to people's calls to seek advice.

Washing and Dressing the Person who Died

In addition to arranging a medical certificate for cause of death, participants also described their experiences of washing and dressing their significant other person. These findings suggest that some people still regard their significant other person as having a sense of personhood in their death.

Participants continued to demonstrate a sense of responsibility and care for the person who had died. The actions of washing and dressing were undertaken with respect, love and tenderness. This was evident in the five aspects of: the handling of a deceased person; the attention given to detail; ensuring a place of comfort; ensuring dignity, and the choice of clothes. The way in which a deceased person was handled was considered important, as highlighted by the following comment made by a daughter explaining why she chose to dress her mother rather than the funeral attendants doing this:

I didn't want them shoving her around, dressing her up.

4

The mother of one infant daughter decided not to change her daughter's clothes because 'she didn't like being dressed'.

I just thought, 'I'm not going to interfere with you anymore. I'm going to let you be'. So, she was in this daggy little nightie. We put her in a little sleeping bag

22

Two participants explained that attending to a significant other person's body was very different to nursing dead people in hospital, highlighting their belief in the difference between the interactions of healthcare workers and significant other people:

And then my two sisters that are nurses and Mum washed him. They did all that. We didn't. We weren't part of that. They knew what to do and how to do it which was big for them because it's one thing to nurse people that you don't know or love; it's another thing to do it to someone you love. 18

It was certainly a very different experience to when you're in a hospital washing people when they die and to tie their limbs to their body and treat them like the deceased. We were still treating [my husband] like he was still alive. 10

Providing a sense of comfort was also important. One participant explained how they used 'soft white fluffy towels' to wash her mother's body. Participants wanted to create a state of comfort for their significant other person, as highlighted in the following comment:

I was ironing his jamas. I know some people go into their coffin in a suit but Mum chose red pyjamas for him. He loved red and they were his best pyjamas and that's what she wanted him to have, so I ironed them. What else happened? Then they dressed him in that and I bought him socks for Christmas and they were beautiful red Explorers because he was getting really cold feet because his circulation wasn't good. We popped his red Explorers on him. 18

Ensuring dignity and respect was considered important. Respect given to the deceased person was evident in the gentle responses and the desire to maintain the deceased person's dignity. These important elements of care are highlighted in the following quotation:

... [my father] didn't have his dentures in, and my sister, they couldn't get his dentures in. And I remember my sister coming out and saying about it; that Dad's mouth, they couldn't move his mouth and stuff, probably because he was so cold, I suppose, I don't know, he'd been cold for days, you know. And she said, 'I really want to put his teeth in and we can't do it,' and of course [my partner] said that he might be able to help with that. He was quite used to doing that sort of thing and so he went in and helped put his teeth in and position his mouth nicely, and so he looked quite nice and not so sunken... 7

Another participant spoke about her friend's support and her subsequent appreciation for leaving as she attended to 'the personal part' of washing her husband's body, thereby ensuring that dignity was still granted to the person in death:

... she was so beautiful you know, when it came to the personal part of cleaning him and he wasn't dirty fortunately. She just left the room, which was so respectful. She was a really good nurse and a very beautiful lady. 10

People also explained how the jewellery belonging to the person who died was considered precious. Most participants removed the jewellery from the dead person and eventually wore the item on their own body. Two participants described their experiences with removing the jewellery, which suggests that no prior conversation about its arrangement had been made before the person's death. In the first instance, being unaware that a person could be buried wearing jewellery influenced a mother's decision to remove a ring from her daughter's hand:

[-] had bought [my daughter] a ring, the Christmas before, and I'd taken her jewellery off her because I thought you weren't allowed to bury people with jewellery on anymore. 19

Another participant regretted removing the wedding ring from her husband's finger, explaining that the funeral attendant had enquired whether she wanted to take it from her husband's finger:

At that point I was in shock, I know now, thinking I was being very rational and I said, 'I don't know'. I hesitated because I wanted to keep it as a keepsake but it was something so important to [my husband] and from the moment I put it on his finger when we got married, he never, ever took it off and my friends said, 'Oh you probably want to keep it. You should keep it'. So I said, 'Yeah, okay'. That's something I regretted because I always felt afterwards I should have been more sensible about it because it was so important to him that I should never have taken it off. 17

The choice of clothes was another feature of washing and dressing the person who died. Washing and dressing a significant other person's body was considered an 'intimate' act. One participant explained how she organised the opportunity for the friends of a deceased young woman to dress and apply her makeup before she was removed from the home. The enactment of applying makeup and dressing the young woman in clean clothes was done as a mark of respect, honouring the life that she had led and reflecting the care and concern that this young woman had taken with her own appearance.

[She] had died and her friends were still there and I said to them, 'We need to wash [her] and change her,' and [her mother] and her friends had chosen a lovely outfit for [her] to have on, and because [she] had lost her hair due to the chemo, she had quite an array of wigs, so, chose a wig for her and a dress, her knickers and all her lovely clothes; so I talked to the girls and said, 'How did they feel about helping me?' and they were very reluctant at first; for a lot of them, this was the first time they had experienced death and to be one of their very special friends, it wasn't easy for them but they were wonderful. [Her mother] didn't want to be in the room; she just didn't want to be involved, so we washed [her] and did all those things and then put her wig on and then I said to the girls, 'I'm not very good with young makeup stuff, you'll have to help me,' and it was so special because they were all up on the bed; I think there were four of them and two each side of the bed making [her] face up; in the end we were all having a little laugh and a little cry; it was so special. Then [her mother] came back in and there were big tears again. 6

Some participants chose not to attend to the washing and dressing of their significant other person, explaining that they 'couldn't face it' or 'I didn't feel that I wanted to do that.' Not being involved in these activities did not stop people from being concerned about their dead person. The assistance from healthcare workers in washing and dressing a dead person were very much appreciated and generally regarded as supportive and appropriate.

There was only one example in the study of a nurse's good intentions being inappropriate, highlighting the need for support workers not to impose their own values upon other people. This example of inappropriate support involves the gesture of placing a carnation on a pillow. The participant explained that the offering did not honour the way her mother had lived her life:

I walked into the room. [My sister] said, 'You go first'. I think she was scared of the dead body stuff. She said, 'You go in,' and I just started to laugh because they'd also put about three pillows behind her head, and this bloody carnation ... I mean Mum hated flowers inside because she figured they are meant to grow outside. They weren't to know it and I appreciated the gesture and the caring and stuff but my Mum was not a flowery, lacy person. She was just an in-your-face sort of person and I knew she would just be laughing at it; this bloody pink carnation ... I said to [my sister], 'Be warned. Check this out. Come in and look at this,' and we looked at each other and I said, 'The flower's got to go,' so we just chucked that out into the bin. 24

The findings from this study demonstrate that regardless of whether people were or were not involved in the washing and dressing of the person's body, the enactment was imbued with intimacy and care. Caring for a dead person is embodied in the actions of people, either through their personal involvement or their trust in a select group of people who have had prior experience of undertaking the tasks of washing and dressing a person who has died.

Contacting a Funeral Director

Another task that participants undertook following the death of their significant other person was to contact the funeral director to assist in removing the person from the home. Knowing which funeral directors to choose was an easy decision for most people based on recommendation or prior experience, as shown in the following comment:

It was Mum and Dad's choice. I think Dad had told Mum... Like, they had been to lots of funerals of other people and they liked that funeral home. They liked the actual building and the way things were done there.

16

One disruption to the data is illustrated in the decisions made by the parents of two infant daughters. In contrast to all the other participants in the study, these people decided not to delegate any responsibility to others in the care of their babies. These parents described the events which ensued after their daughter's death:

And then it got to the point that we thought we'd better ring up a funeral home.

We were a bit unsure about bodies and what they did when they were dead. We certainly didn't want to have her there and doing something scary on us, so I rang the funeral parlour to find out what we should do for her. And he said, 'Just give her to me for the night. And then I'll bring her back to you,' and I thought, 'No'.

She'd been poked and prodded enough...

'You're not taking her. She's not leaving. I just want to know what to do with her'. He was quite strong; quite forceful about it. 'I'll come and get her; look after her and then bring her back to you'.

Then we talked to a lady about death...

[-] a grief counsellor at the hospital.

She said you can do whatever you want. Keep her at home.

Yeah, she was wonderful...

No, she wasn't at the hospital; she was with Palliative Care. So we kept her home until the funeral. 22

These parents made sense of the funeral attendant's behaviour in terms of finances:

Well, we decided after talking to him that it was all about money.

Yeah.

The funeral parlour's money and he wanted her out there for the night so that he could charge us.

Charge us for having her.

That's all and that's why they might want them in the parlour because they charge for every day they've got them in there; I don't know. But there's no practical reason why you have to be rushed. We found out how long we could have the body in the house. It was up to seven days, I think. 22

In contrast to the experience of the parents of the two infant daughters, most participants in the study found their funeral directors to be 'supportive', 'good', 'sensitive', 'efficient' and 'caring':

... when daytime came, [her mother] asked me to ring [the funeral directors] which I did and I rang [-] from [-]; he had been with us when [our grand-daughter] died and he was just wonderful; so I rang [-] and he said 'Well, it's my day off,' and I said 'Well, it's not anymore because you've got to come and do this for me,' and he said, 'Sure'. So he came about half past eight, nine o'clock and he spoke with [her mother and father] and they organised the funeral, which was to be on the Monday and filled out all the necessary forms which have to be filled out and he was very, very kind and understanding and very good with the family. 6

In the next example, a participant describes how she and her husband interpreted the service provided by the funeral directors in relation to attending to their son:

We kept [our son] there for over two and a half hours after he died and when the funeral directors arrived we found them to be very sensitive and caring, dealing with the situation with dignity. 27

The prime reason for engaging a funeral director at the time of death was to remove the person who had died from the site of the home. The majority of participants in this study organised final arrangements with their funeral director at a later time than the actual removal of the person's body took place, most often within the following two days.

Seeing the Deceased Person Leave the Home

The findings from this study show that one of the most challenging experiences that people endured throughout the time of death was witnessing the removal of their significant other person away from the home. In the findings, several aspects of this experience are evident, including people's different responses, the behaviour of the undertakers, and the logistical problems transferring the deceased person. Responses from people varied. For several people, regret was expressed in relation to the haste in which this episode transpired:

[My husband] died at twenty past ten on that Sunday night and they were there within an hour and a half... I thought that was a bit quick. I would have preferred them all to go away and leave us alone and then come in the morning, you know. I wasn't too keen on that. So, I got them to pull the blanket back and I gave him a big cuddle ... but I thought that ... I was too much in a daze; it was too quick, too sudden. I think they should just ask if you want to be on your own for an hour or two.

2

Two other participants shared a similar understanding in that they were unaware that a deceased person's body could remain in the home for a period of time after they died:

I think if I had to do it over again I would have left him at home until morning the next day, but I didn't know that you could do that. I thought someone died and then you called the funeral home and they come and take them away.

17

People experienced the same event differently and some people expressed relief. In the following example, a participant spoke of her sister's and her own response to their father being removed from the home.

I really did feel a sense of relief. I mean, I know my sister really struggled with it; she broke down and I remember sitting next to her and she was just shaking; she was just so distraught at that time; she really felt that loss at that minute and yet I just didn't feel that loss at that point. 7

A third of the participants in this study applied the word 'difficult' to describe the experience, as shown in an excerpt from a mother's narrative:

The time had come for them to take [our son] from his home for the last time, but before he went, everyone present, including my brother and sister-in-law and two nieces, said goodbye to a very brave little boy. Some found this to be a very difficult experience, for it was for many the first time that they had experienced death firsthand. The fact that it was a child probably made it even more difficult. My two nieces and [-] both touched [our son's] hand and said a simple goodbye, and while several of the adults present were able to kiss [our son], others found that a simple touch was all that was possible. 27

Other participants who spoke of the removal of their significant other person from the home referred to it in terms of being 'hard', 'awful', 'distressing', and 'sad':

They just picked [my wife] up, put her in a body bag and took her away. It was not nice at all. Actually, it was distressing. 9

In the next example, a participant explained how seeing her sister put into a body bag was 'the hardest part of all':

I think the hardest part for me anyway, from then, was when they did come, was putting her into the bag. I think that was the hardest part of all. I coped really well and I mean, I just went about my business in the house; cleaning up; tidying up; packing up the stuff that we didn't need; my sister-in-law went to bed but I couldn't, so [her husband] and I sat there with the windows open just where she was; but when they put her in that bag and took her away, that was the part that I hated most... But I don't know what else you would do. And of course, they had a very steep driveway and they couldn't bring the trolley upstairs. We had to take her from the lounge down to the front door and then [her husband] and I; he and the man nearly dropped her, actually. I mean, that was a light moment for a second, really, because they had to laugh. Because, I mean, you do, don't you? You do a lot of laughing as well as a lot of crying 26

Another participant spoke of the experience with humour, but still explained that she did not find the experience pleasant:

When they took him, they took him in a green corduroy bag thing on a stretcher, and I thought, 'Oh, I don't like that'. But we laughed because Dad used to have corduroy trousers, so it would have been appropriate. 18

A fifth of the participants in this study felt uncomfortable that their deceased person was transferred into the gaze of the public. The uncomfortableness of this experience is described in the following comment:

I had this stupid thought that it was better in a way that [my husband] went out when it was dark rather than have all the neighbours see him be moved in the daytime. But you know, that's just a silly thing. 2

In the next example, a daughter recalls her response to her father's body being taken away from his house, and reflects upon how contemporary society sequesters evidence of death in the community:

Yeah, that was weird, that was exactly how it is, you know, in movies when they put the body into a bag and the body is carried out and the hearse comes to the house. And I was, like, 'Wow! That's really in your face!' It's really out there for public viewing, isn't it, and they carried Dad down the front of the house for the whole street to see. I don't know if anyone did see, but it was certainly out there and that was a strange thing; it wasn't a discreet process at all. I suppose because I had never witnessed it myself, I just sort of assumed these things sort of happened in the middle of the night. I'm not saying it's wrong that it happened this way; it's probably a good thing that way, unless of course a child on the street saw it, but death is the one definite in life, isn't it! And as our culture pushes it aside, I think, so we don't necessarily cope with it in a positive and functional sort of way. 5

The second aspect in seeing the deceased person leave the home concerns the behaviour of the undertakers. One participant described the experience as 'lovely' on account of the person's body not being completely enclosed in the body bag:

... but when they took [her] away, it was lovely. They did what they had to do; popped her into the bag they had to but only zipped it up part of the way. 6

Several participants described the undertakers as 'respectful':

I do remember the undertaker, I guess you would call him, I remember my friend said, 'Oh, can you just give us longer?' and we thought alike and anyway, there was like this pervasive sense of you know, 'They've got to take him away,' and I would have to say that was the hardest thing, allowing him to leave. That was awful... Poor man that had to do it, you know. I felt sorry for him that we delayed

him in his job but he respectfully, quietly, said nothing, but hovered and I can remember looking him in the eye and saying, 'You look after him'. I just wanted to say, 'Don't treat him like the attendants would in the hospital. Don't just shove him anywhere. You look after him,' and I can remember I substituted the pillow that he laid on and just held that close to me for the rest of the night. 10

Another participant spoke about her experience with the funeral attendants taking her mother's body from the house. She described herself as being 'very involved':

They came in and they were very respectful and said, 'Do you want to go to another room or whatever?' and I said, 'No, no, no, no'. [laughing] In came the trolley... So they put her on this trolley and in this giant plastic bag and just as they put her on this plastic thing, her arm fell off, so I just picked it up. I was amazed at what I was doing. An absolute compulsion to do it and I kind of tucked around her and tucked her in like a little kid as if I was trying to make her comfortable and they went to take the teddy away and I said, 'No, no. It has to go with her and I have to trust you that it goes with her the whole way because it's incredibly important to me and it's very important to her and it has to go with her'. Then I kissed her goodbye and they wheeled her out. I think they were more in shock. I just couldn't do anything else. It's what I had to do. Mum's house had walls around the garden and big gates and they had backed the vehicle in and everyone else had done this disappearing act and I saw her off, into the back of the car and I just stood in the driveway and I waved and blew kisses. It was just the stuff I did. It was automatic pilot. It was just what I had to do. 24

Participants explained how removing a person's body from the house often created logistical problems, creating the fear that their significant other person's body could be dropped as it was being carried away from the house. The following example demonstrates how participants experienced this event and the anxiety it created:

... and the funeral directors came and that was hard for Mum, taking his body from the house ... but of course, their house, there's always stairs, isn't there, steep stairs to get off a verandah down to the yard and fairly cluttered with flower pots and things. Again, that sort of hysteria around, 'Oh my God, he's going to roll down the thing!' and of course they've got them strapped on, but you know how your mind goes... 1

Stairs or steep descents featured in almost a fifth of participants' stories. In the following example, a participant explains that the funeral directors said that they would have to carry her mother down the stairs, stating that she found this experience of seeing her mother leave as 'awful':

... it was an upstairs house that she lived in and the stairs went down and around and out and they said 'We're going to have to put her vertically to get her down the stairs. Is that okay?' and I said 'Yeah, that's fine' and I didn't have an option, so they were kind and they explained it, but it was just an old Holden panel van sort of thing. I watched it drive down the end of the road and that was the end of it. Yeah, that was awful.

4

One participant explained how her grandson expressed concern for his grandfather's well-being leaving the home:

We were almost at the bottom of the stairs and [our grandson] said, 'Why did you zip my grandpa up in there because it will be pretty dark?' [-] immediately said, 'We don't want the people outside looking at him now he died, do we?' And [my grandson] said, 'Oh no, okay,' and walked out with them and then of course he wanted to see if they were going to put a seat belt on him. They had the belts to put over and he was quite satisfied when he knew Grandpa wasn't going to be going like that, without a belt. Yeah, I thought it was lovely because he knew he was dead but he wanted him to be secure on his last bit of a journey.

23

The findings from this study suggest that people valued the following responses from the people who attended to the removal of their significant other person from the home: collaborating with people in a sensitive and compassionate manner; being responsive to the wishes of participants; their ability to offer competent and reliable information; and their willingness to remain in the background at the scene of death until asked to intervene.

Concluding Comments to the Chapter

An imperative for people at 'The time of Death' is to 'Be present', to companion their significant other person and witness the event of death. Attending to the death and dealing with the dead body of a significant other person in the site of the home involves a complex interplay of biological, corporeal, spiritual and social factors. Heightened emotions and an acuity of perception meld with these factors to create an intensely personal and profoundly emotional experience for people. For some people, the experience transpires in a way which offers peace of mind. For others, unexpected outcomes may precipitate consequences, thereby causing distress and adding to the

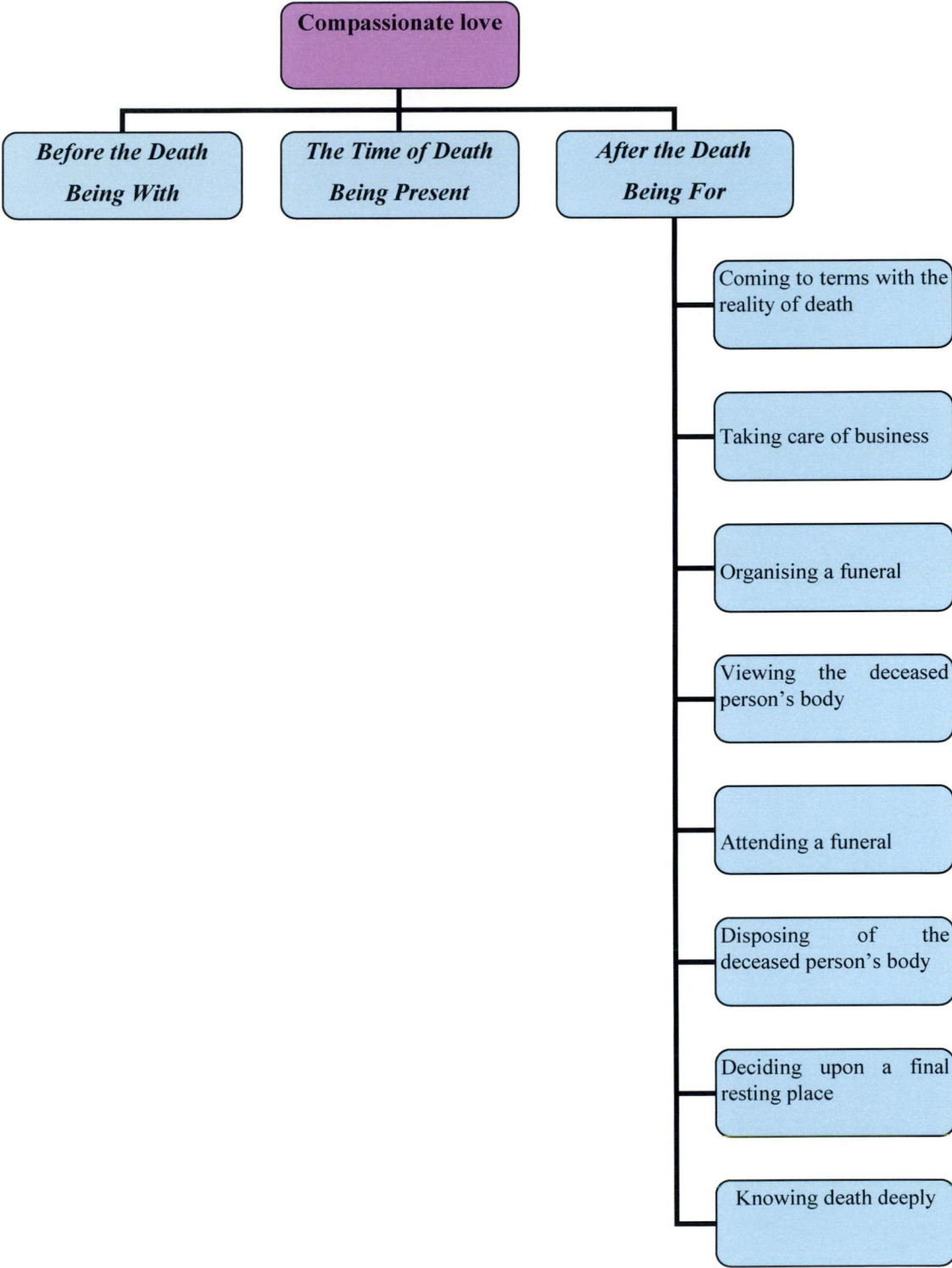
bereaved person's grief. Despite expectations and purposeful planning, a death may not always transpire in a way that is anticipated. A common experience for participants throughout this period was the challenge they confronted in delegating the responsibility of their significant other person to someone outside of their home. The time following on from this period is referred to as 'After the Death' and is characterised as a period in which people have to make many decisions. This period is concerned with death matters which occur in response to a person's death and is explained in the following chapter.

Chapter 9: After the Death — Being For

Introduction to the Chapter

The period known as ‘After the Death’ begins when the body of the deceased person moves away from the private space of the home into the public domain. By virtue of death, people now enter a time of early bereavement and their attention is focused towards making final arrangements. This period is characterised as one in which people have to make decisions on behalf of the person who has died and is described experientially as ‘Being for’ the deceased. There is no assigned end point to this period, as caring may continue for the deceased significant other person throughout the lifetime of the bereaved. This chapter focuses predominantly on the time surrounding the funeral. A brief discussion of the ways in which people memorialise the life of their deceased is also included. The following figure (Figure 4) illustrates participants’ experiential accounts throughout ‘After the Death’.

Figure 4: Participants' Experiences after the Death



Coming to Terms with the Reality of Death

There are three key aspects evident in the category of coming to terms with the reality of death. These are: accepting what has happened; having a strong urge to engage in certain activities; and experiencing overwhelming feelings. These aspects would often overlap, bringing little respite to people in the time following the death. Participants explained that coming to terms with the reality of their loss was not a fact which could be easily processed as demonstrated by the comment of a mother who recalled the surreal nature of her son's death:

When [our son] was removed from the house, I stood by the door and watched and I remember thinking that it was like a play and that the curtain would come down, everyone would take a bow, [our son] would walk back in and all the actors would sit down and discuss how the play had gone. Reality returned and I knew that this was no play, that this was real ... 27

Participants also knew that they had no alternative but to adapt to changed circumstances. In the following example, a participant explains how difficult it was to mentally process her father's death, particularly in light of the unrelenting weeks leading up to her father's demise:

Anyway, my sister came back out and we all sat down and had a cup of coffee and it was just like you couldn't believe it was over. Because it went on for every day, you expected it to be the last day and then when it wasn't the last day, you started to think, 'Is this going to end?' 16

Rather than use the word 'accept', some participants used the word 'realise' to describe knowing that their significant other person was dead. In the following excerpt, a participant realises that the death heralded other responsibilities which she would soon be compelled to undertake:

I think the crunch came for me, I'd stayed very calm and very positive. When they wheeled [her] out to the van to take her to [the funeral director's] and put her into the van and I hugged her and kissed her and then I cried and I think the enormity of the whole time or the last twenty-four hours had hit me and I realised, yes, [she] had died now; we have to move now to the next part, which is the funeral and the grieving time; that side of it and I did cry and [her mother and father] both cuddled me and said thank you, couldn't say thank you enough, and then they had a cup of tea. 6

Several features became evident in the activities that people undertook following the death. People described sleeping, eating, drinking, tidying up and contacting other people to notify them of the death. Sleeping featured in a quarter of participants' experiences and sleeping in the bed of the deceased was a common experience, whether it was shortly after they had departed from the house, or in the days, weeks or months following the death. These findings suggest that the bed can offer comfort to people by enabling them to feel close to the person who died.

In the next example, a daughter describes how she returned to her mother's bedroom to notice a peculiar smell emanating from her mother's bed. Later that evening after changing the bed linen, she retired to her mother's bed for the night:

I think I turned around and went inside and I noticed the smell on my mother's bed. I thought, 'Will I tidy it up a bit? Will I strip it? What will I do?' I just pulled the bedspread up but I noticed a funny smell that I hadn't smelt before. I've discussed it with [my friend] because he'd had sixteen years in the police force and he's unshockable, so we discussed this one day and he said, 'Yeah, it's sort of an acrid unusual smell'; not stale but very hard to describe. It wasn't like sweat. Amazing how I had to get into every detail, and that night I slept in the bed. I obviously remade the bed and everything. I think my siblings were appalled but I needed to do that.

24

A fifth of the participants in this study also explained that they felt an urge to clean, pack up or pass on personal effects and equipment after their significant other person had been removed from the house, as shown in the following excerpt from one daughter's narrative:

I just started cleaning up. It was like you just had to keep moving, had to keep doing and I'm not really a house cleaner. It's not really up there on my list of things to do. If I've got something else to do, it's not really something I wish to do. It's only a necessity. I just jumped in and started putting things back to the way they should be; vacuuming and cleaning up; gathering up the things that had been left by palliative care and putting them in the spot to be taken away and Mum did the same. She wanted everything gone from the house, then that day and they came and picked it all up. It was like you wanted to remove all that gear.

16

People's experiences in early bereavement also included notifying the wider community of their significant other person's death. Telephone calls, emails, personal

correspondence and newspaper announcements were standard ways of conveying to others the news that the person had died:

I made lots of phone calls. I started calling friends... I had lots of business associates and people to call and it took the longest time. I was telling [-] just the other day that after he died, I mean starting that first morning, people were calling and I was taking phone calls and I was getting hundreds of emails per day from all over the world. He was a mentor and he was a pretty unique person in his energy and I think everyone sort of connected to that ... I loved it and I think that it really kept me going; gave me something to do; I'd get up in the morning and get straight into the computer and start doing the emails. People would write and they wouldn't just write a story about [him]; they wrote and said, almost all of them said, 'I knew [him] from [-] and I have to tell you this story about him'. 17

Whereas some participants found conveying the news of the death to others a gratifying experience, other people described this task as 'hard', 'strange', 'awful', and 'bizarre'. The dissonance between witnessing and being able to articulate was highlighted by one participant who attended her father's death:

I remember thinking that it was hard just to say that he's died, even though we had been there. 1

The findings from this study suggest that communication can be an onerous task for some people throughout early bereavement:

I remember [my partner] and I, after Dad's body had been taken away and I'd phoned [friends and family] about the funeral and all that kind of stuff, all the things that you have to deal with afterwards, we went out for dinner. That house seemed weird because I'd grown up in that house and it seemed empty; it was quite a weird experience and we went out to dinner and we couldn't even speak to each other, 'cos [my partner] was there when Dad had died and it had been a horrific night beforehand and I remember us going out to dinner to a hotel in [-] and yeah, I can't remember what we ate or where we sat, and I just felt totally depleted and I suppose that's the way I'd describe the experience and I couldn't give any more, kind of thing. And we couldn't talk, like, we'd been up all night with Dad. It was just a full-on experience. 5

Almost three-quarters of the people in this study described feelings of exhaustion:

Then they took her away and then I came home because I guess I was totally drained ... and just slept for twenty- four hours. 26

‘Exhausted’, ‘depleted’, ‘drained’, and ‘on automatic pilot’ were terms used by participants to describe their overwhelming fatigue. In addition to the exhaustion and of being kept busy, people also spoke about being ‘angry’, ‘numb’, ‘in shock’, ‘running on adrenalin’, ‘spaced out of my brain’ and ‘neglected’ in early bereavement. Being trapped in a state of limbo was a common experience. Feelings of being separated from normality became commonplace, as encapsulated in a passage from a participant referring to his early bereavement:

I was virtually in a trance. Although [my wife] had had a long sickness and she was dying, when she actually died, I felt gutted, absolutely gutted when she died and I can remember walking across the street and cars were blowing their horns at me... I can remember one chap leaning out of the window abusing me, which he had a perfect right to do. I had no qualms about that. I mean, I was just in a trance.

9

The feeling of being separated from normal life is further described by a participant who recalled the days leading up to and following her father’s death:

The thing that I noticed was that time was really different; some things seemed like time moved really slowly and others moved really quickly. It was a time of being not particularly aware of what was going on around us. It’s almost like we entered like what was a time capsule; felt cut-off from the rest of the world, it felt very much the centre of its own world. I don’t know if that makes sense... It felt very cut-off and it was very cut-off from my normal life, ‘cos I was out of my environment, but [my sister], who wasn’t, said it was very like that too. She felt, she went to work but she wasn’t really at work. She felt like she was in a bubble and that’s how I felt, really, like we were all in this sort of bubble in which there were a lot of emotions but you weren’t really tuned into the world, like the colours weren’t acute or right, everything was a sort of a bit muted. It was a very, very strange experience.

1

Several participants explained that events transpired too quickly following the departure of their significant other person. These experiences created a feeling of being rushed, making decisions in haste and of not being in control, as demonstrated in the following excerpt:

... it’s a bit like a runaway train ... Like Dad didn’t die until a quarter to two in the afternoon and this was like five thirty and I don’t even know how that happened; I don’t know how that happened. I don’t know who arranged it, or if it just happened in the conversation when they came to get the body or what. It just sort

of all snowballed ... I just remember thinking it's just all moving so fast and even to think that we were sitting with this guy at a quarter to six trying to put notices together.

7

One participant described how she had to control her emotions so that she could deal with the demands that beset her in the days following her husband's death:

I remember sobbing that night with my pillow and crying really hard but then probably returning to this stoic functioning, efficient person that had to unfortunately carry the load of doing all the decisions singularly.

10

In the very early stages of bereavement, people began to make major decisions. In the next section of 'After the Death', the legal and financial obligations that evolved as a consequence of the person's death are highlighted. This section illustrates how such demands are experienced simultaneously with early responses of grief.

Taking Care of Business

Several aspects are evident in the category of taking care of business. These aspects include: the contact made by participants with other agencies, in particular lawyers and professionals who manage financial matters; the stress associated with attending to these matters; and the lack of respect some people experienced when dealing with these agencies.

Financial and legal matters are closely aligned with the undertaking of final arrangements. People were either contacted by an agency or they made an appointment to see a solicitor, lawyer or accountant:

There were so many formalities to work through in terms of people and organisations to be contacted. I think I had an A4 sheet on every line with somebody different, or different organisations, insurance companies, Centrelink, that was a classic that was. I mean, actually, it took me quite a while, quite a long time to get financial support, you know, being a fulltime carer and I think it came through about two weeks before he died and then doing the right thing, like, it says if your circumstances change you must inform us.

3

In the following quotation, one participant explains how he visited his solicitor the day following his wife's death:

I had to see the solicitor because all our belongings, absolutely everything, was in both our names and I wasn't quite sure whether I could sign cheques or whatever, so I went to my solicitor just to — this is the next day — to find out what I could do and couldn't do and my solicitor said just to carry on exactly the same way you've been. There'd be no probate to pay and the only thing now, it won't be in both names. You'll have to get the bank to change the name to mine on the cheques; her name will come off everything but apart from that you can just carry on. 9

Most people explained that their contact with agencies added to their stress throughout early bereavement. In the next example, one participant describes this experience:

It's like a conveyor belt you step onto. The next thing was a phone call from the solicitor to say he'd seen the notice in the paper. I've made an appointment, come in and see me. You know, and the next thing's the accountant... people want things of you all the time. 2

Three participants explained how financial issues resulting from the person's death continued for some time after their significant other person had died. For these people, the stress and anxiety associated with these issues has been long lasting:

There was one very down side after [she] had died. [Her mother] notified the superannuation people and they were very, very, very difficult and said that the death certificate wasn't sufficient. They wanted a post mortem. And by the time, like six weeks after [she] had been cremated and I mean they wanted her history, the whole works, before they would sign over [her] superannuation. In the end [the medical specialist] was very supportive and very good and [her mother and father] had to get a lawyer; disgusting. It has now been settled and that was just traumatic for the family. They will remember that. 6

Another participant described how her husband died intestate. Leaving no will created conflict over matters involving inheritance. 'Terrific anxiety' was one of her responses to this traumatic experience:

Oh, hideous! There was no resolution. There was no closure because he left it in a mess. It was a bad will and he knew... there were a lot of things to-ing and fro-ing to solicitors and things for years and years. I remember my family saying, 'It's an equity battle; it will go on for years'. 'Oh God!' I thought. 'I'll be in a caravan park and destitute and it's not fair. It's not fair... Why me?'... then when the

affidavits and the summons came by special courier from this [-] fellow; here you are right on Christmas Eve. Happy Christmas! And I couldn't see a lawyer until the end of January. So I thought, 'Oh, he's suing me. I can't bear this. How am I going to get through it?' 11

More than half the participants in this study reported at least one unpleasant interaction with an agency or service provider with whom they had contact as a consequence of their significant other person's death. The first example illustrates how one participant received incorrect information:

I went to the bank with a medical certificate for cause of death signed by the doctor but they wouldn't accept it. They said that I had to go and get a death certificate, which would have cost me about seventy-five dollars. Anyway, I went down to the lawyer and he said, 'No, I'll write you this out. You take that. You don't have to pay out that money'. 13

Many participants explained that they encountered a lack of respect from the agencies which served them, demonstrated in the following three examples:

I rang them up and I got somebody, a male on the other end, 'Oh, we already know thank you', and put the phone down. So that was a real slap in the face. No 'Oh, I'm sorry to hear about your loss,' sort of thing, because they have somebody checking through the newspaper, don't they, so a few incidents like that, which were difficult to deal with and, as I say, there were so many letters to be written that I was busy with the business side of things for quite a while. 3

Oh Social Security; unbelievable, absolutely unbelievable ... just awful because they treated you like you were some sort of second-rate citizen and there was no compassion; no nothing. It was like, so what, that [your father's] dead, we want our money back. That was awful... Stressful; very, very stressful because you were pretty raw emotionally... and you're dealing with people who really couldn't care less and really all they're interested in is so long as they get back what's theirs, is all that matters. 21

... some of the ways that I was treated, I was just shocked. Not always; a couple of people treated me really well with empathy and compassion. For example, I remember I filled out a form and it showed that [my wife] had died and the person said to me, 'How much money did you get out of that?' That was the only thing that was said and I just couldn't believe it. 25

Another participant explained how a solicitor embezzled her father's financial investment and how she was unable to recover all the money:

It was horrendous, absolutely horrendous. That was probably the worst part of it because I sort of thought to myself, 'Now, he's worked hard all his life'. The money to me is neither here nor there, Marg, I don't care. What I've got, I've got and what I haven't got, I haven't got; but to think that that mongrel got it. 21

In early bereavement, people's attention was not only directed towards financial and legal matters, but also towards final arrangements. The next section describes people's experiences of arranging a funeral.

Organising a Funeral

In the days following the person's death, the time was dominated by decisions regarding the funeral. These decisions were complex and varied, and usually had to be negotiated with other people who sometimes expressed differing opinions. Decision making was shaped by a variety of influences, including a person's faith, individual values, influence from other family members, financial circumstances, the wishes of the deceased, available resources, and prior experience of having organised or attended a funeral. Some people single handedly organised the funeral; others were assisted by family and friends; and three people played very little role in any of the funeral arrangements despite having been the primary carer throughout their significant other person's illness. The findings in this study show that despite there being a wide variety of approaches to funeral practices, the purpose of the ceremony is to give expression to the change in people's lives, to facilitate the disposal of the physical body by way of cremation or burial, and to commemorate the life of the deceased person.

Organising a funeral has several key aspects, including planning for the funeral and honouring the life of the deceased person through decision making about choice of clothes, the casket, coffin or urn as well as other accoutrements, and the actual service. The first part of this section attends to how people negotiated the planning of final arrangements.

When discussing the organisation of a funeral, almost half of the participants were unsure what words or expressions to use, as illustrated in the following comments:

- ...at the graveside, I don't know what to call it, really.* 1
- ...then we had a celebration of her life or whatever they call it...* 8
- ...She said she wanted a, what do you call it, a civil...?* 9
- ...I had to write the sermon, what do you call it? Obituary?* 10
- ...the undertakers or whatever you call them.* 14
- ...handouts; whatever you call them, service things.* 16
- ...we didn't have set pall bearers, that's what they're called, aren't they?* 25

These comments demonstrate that the language associated with final arrangements is not common currency amongst the people in this study. Not being familiar with the language suggests that many people have had little or, in some cases, no prior experience with arranging a funeral. It is feasible, therefore that the stress of arranging a funeral may be amplified by not being accustomed to final arrangements.

Some participants explained how they became involved in the preparation in the years before the diagnosis of their significant other person's life limiting illness. For half of the participants in this study, the diagnosis of a life limiting illness was the catalyst for initiating discussions and making plans for final arrangements. In the following excerpt a participant recalls how she discussed with her husband the preparations for his funeral:

I think he'd been home for a week or so. I just sort of said to him, 'Look, I hope you don't mind me saying this but being very sort of ignorant about what has to happen, do you mind if I go out and do some homework?' So, I went around to the three funeral places I found in the yellow pages, because I don't think I've been to a funeral here, and sort of found the one that I was comfortable with... I think that was part of what was in me to want to do things right, and I suppose in a way I have tended to do things either as a couple or on my own. I haven't sort of sought help from other people in that respect and I chose a casket and decided upon a celebrant and I actually invited the celebrant to the house to meet him before. 3

Organising the funeral was not necessarily a solemn experience for people; sometimes it was undertaken with humour. One participant remembered an amusing moment with her sister concerning the music chosen for her sister's funeral service:

She picked all her own music ... put [it] onto a CD and the last day she was compos we were playing it. She said to me, 'Put that music on for me,' and I put it on and I said to her, 'Well, I bought my funeral music up and seeing you're not going to be here to listen to it, do you want to listen to it?' So I put it on and she started crying. I said, 'What are you crying for?' She said, 'Yours is nicer than mine'. [laughing] Yeah, so she had all her music ready.

26

Some people who were dying organised what to wear for their funeral or how to distribute their personal effects. One participant explained how her daughter organised to give away her possessions before she died, having already arranged Christmas presents to be distributed amongst her family several months following her death. Another participant recalled a discussion with her husband regarding the clothes in which he would like to be dressed in his coffin:

I asked him before. I said, 'Do you want to go in your sports gear or your best suit?' and he said, 'My best suit, please' ... we did talk and it was quite comfortable, actually.

3

For the people who gave consideration to their clothes, the style of garment was usually important. In the following example a mother explains how her teenage daughter was actively involved in organising what she would like to wear after she died:

She'd organised the clothes for the funeral. 'I think I'll wear these pants, Mum, and these shoes.' ... She wanted these cream pants and her platform shoes because they made her taller. She was the shortest and she didn't like being the shortest, so she had the platform shoes; a white camisole top. She said that it wouldn't look white because she had a brown long chiffon shirt thing that had to have it buttoned up, so you wouldn't see the white.

19

Another participant explained how she and her brother bought a nightdress for their sister to wear:

... my brother and I had decided that we wanted to buy her, her nightie to be buried in and when it was for \$380, I said to her, 'I'm only paying half of that' [laughing] but anyway, she's trying it on and, you know the lady in there, because

she's a friend of the family; we all know her, anyway, she said, 'Oh, is there a special occasion?' [My sister] said, 'Well, actually yes, I'm going to be buried in it.' And if you had seen this lady's face; I'm sure she nearly died on the spot! So anyway, we came out of there with this beautiful box with this absolutely magnificent burgundy negligee; absolutely beautiful...

26

Having been able to discuss the final arrangements with their significant other person gave some participants a sense of relief and comfort throughout early bereavement. One participant described how organising the final arrangements with her husband in the 'Before the Death' period gave her strength to persevere in the days between the death and leading up to the funeral:

I knew without a doubt right down to the last dotted 'i' what he wanted and I was able to do it. And that is what kept me going: just knowing that I was able to do exactly what he wanted ... If I hadn't been so clear in my mind what he needed or wanted, I'd have been no good at all. I'd have been in shreds.

15

Another participant explained how honouring her mother's wishes was 'all that mattered' to her:

My mother planned her whole funeral with the family. She didn't want flowers and she didn't want a preacher and so we took the service. It was okay. It was okay because it was what she wanted and that seems to be all that mattered.

4

In contrast to those experiences of knowing what was needed were the experiences of twelve participants who explained that organising final arrangements before the death of their significant other person was either intolerable, awkward or unmanageable. Some people found the reality of their loss too confronting to contemplate in the pre-death period:

...people wanted to talk about afterwards; I didn't want to talk about afterwards. I was caring for him, looking after him. If you're the person doing that you can't talk afterwards, you've got to talk about now; this day; this minute ... I think I might have just shut that conversation off because at that point I didn't think that I could stand it.

2

Dealing with the reality of what transpired each day throughout the illness was cited as being all that some participants could manage:

Well, we didn't really think about it at all, even though we had notice; advance notice, didn't we, until the last moment. I think we were just so in shock and grief about her leaving us that we didn't really think about anything like the funeral. 22

Some of these participants felt that it was disrespectful to discuss the death of their significant other person before the person died:

... during that period I can remember feeling really guilty talking about the funeral to Mum's friend ... I felt that was a premature sort of thing to do, 'cos he was still there. He was still there ... like he was there but he wasn't there, kind of thing. 5

Other participants explained that they were guided by the actions of their significant other person. People would not pursue the topic any further when they understood that the subject was not welcomed:

I can just remember he sat on the step and said, 'I don't want to die. I just don't want to die,' but the difficulty of extracting information from him about wishes for funerals and so forth was very difficult when his sole sentence was 'I don't want to die'. 10

In the next example, a participant explains how her daughter rejected any discussion about her death and what she wanted for final arrangements. As a mark of respect, this participant did not pursue the topic with her daughter:

Sometimes of an afternoon when I got on top of things, I'd go in and lay on the bed with her and we'd talk about different things but she always pushed it into the background. She didn't want to talk about it at all. Talk about anything else but ... 12

The close and intimate connection between people sometimes made it difficult to discuss the topic of final arrangements. Several participants explained that the topic of death and final arrangements was easier for their significant other person to discuss with other people with whom they were not intimately related.

People's reactions to organising a funeral varied. Some people experienced feelings of regret; others found the experience cathartic; some found it stressful. In the first instance, almost a quarter of participants expressed regrets about the organisation of final arrangements and for some this involved not discussing final arrangements with their significant other person prior to their death. The following excerpt is taken from a participant's narrative about her father:

The biggest regret that I have of the whole process is that Dad never talked, never admitted that he was going to die and he never ever talked about it. So we had no instructions from him about what he wanted... Maybe because he knew that we were all emotional and he didn't want to have the emotion. I think he just liked to have the belief that he was always going to have tomorrow... I found it really difficult after he passed away and we were organising the funeral and it was just really hard.

16

Two other participants explained how some of the final arrangements were discussed but in hindsight wished that more could have been explored. Serious issues such as financial concerns and a fear of what lay in the future kept the topic of final arrangements at bay. In the following example, a participant recalls how and where her husband wanted his body disposed of, but laments not having been able to further discuss other details of final arrangements:

All he wanted me to do was to make sure that he was buried on the property... I mean you go and make your will. That's the first sign that things have got to be sorted and this is the way you would like things done but there is never a specific moment to which you tend; it's like you get through the night, a little reprieve; a little day longer... If I'd been older, maybe, like, if I had more time with him and the situation had been more comfortable and I didn't have so many other practical worries like money, I might have done it. I would have done it, because you know when you're sixty-one or sixty-two, of course you feel a lot more of life, and you suffer more and you know you can be more compassionate and you can probably find the words. But at the time I don't think I had the words.

11

One person who had described the death of her significant other person as 'a most horrific obscene passing' found the experience of organising the funeral 'cathartic':

I sat up all night the night before his funeral and wrote his obituary. It was done with a great deal of love. You know it was a very positive and very cathartic thing to do. 1

1

In contrast, another participant found that the funeral arrangements were stressful and 'hated the whole time':

I didn't cope very well. I got very annoyed with my other family because they all disappeared. They all went home and my sister went home because she had a son at home and her in-laws had been there looking after him and sending him to school and stuff which intellectually I understand. She had to go home. She's got young children and she needed to be home, in her own home with her husband and things like that... The next day we had to go to the funeral home and organise all that sort of thing because he died at night, so the next day we had to go up there and do that. So all the family went to do that, but then we came out of the office into the car park and they were all going off their separate ways. They were all going home and I thought, 'Well, who is going to do the arrangements? Who is going to do the eulogy?' 'Oh, you can do it. We'll input but we trust you.' ... But I guess I was just really annoyed that people just expected that I would do it. 16

Three participants found that they had very little to decide in the days leading up to the funeral on account of other people in their family assuming the responsibility for the arrangements:

Her funeral was on the Friday; she died on the Tuesday, I think... I was numb, but I did sleep... everything happens. I don't know. If I had to do all of the arrangements, organise the minister, organise the paper, organise [the funeral directors], I don't know if I could have done it. You know, I was lucky, even though I didn't agree with all of the things they did, I didn't object. I really don't think I could have done it. I just went along with it. Yeah, just did whatever had to be done. 8

The findings from this study demonstrate diverse pathways for the way in which people negotiated preparations for final arrangements. Broaching the topic and planning with their significant other person was unproblematic for some people, whilst other participants found the experience difficult, and in some instances, impossible.

The next aspect of organising a funeral involves honouring the life of a significant other person, drawing attention to the factors which influenced people's decision making. Decision making was often based on sentimental and financial reasons in combination with knowledge gained through prior experience. In the following example, a participant explains how the coffin was selected:

We'd ordered a lovely bright blue coffin for [her] because [her mother and father] were unsure about what sort of coffin for [her] to have, and being blue, [her] favourite colour, I remembered they had painted a hot pink one for [our grand-daughter] and I said to [the funeral directors], 'Can you do a blue one?' and he said, 'We sure can,' so blue, bright blue and just white flowers, so that was very good.

6

Honouring the life of the deceased was a powerful influence in decision making, as demonstrated in the following excerpt which refers to the coffin that one woman chose for her husband:

And we insisted on a cardboard box coffin and that was because he had a real thing about trees being chopped down; so a lovely wooden box and then to get it all sizzled up or put into the ground, so we insisted on — I keep saying 'we' — because I felt like he was helping me. He knew I'd do what he wanted.

23

Decision making was also related to finances and a desire to maintain control. A quarter of the participants in this study referred to the cost of making final arrangements. People's expenses included such items as: the casket or coffin; the burial or cremation; newspaper notices; flowers; the venue; catering services; transport; mortuary care; and other professional services provided by the funeral director. In the following two passages, both participants highlight the expenses which can accrue throughout the decision making process. The first participant makes mention of the importance of spending money wisely when choosing merchandise:

Oh, that's a horrendous deal, isn't it! You sort of go in there and there's so much to choose from ... I mean you walk in that room and there are all these coffins there in front of you. I really think, at that stage, some of those funeral people play on people's emotions because they say this and this and this and a lot of people at this stage are not in an emotional state to make any decision.

21

Another participant refers to the funeral director's role in planning for her father's final arrangements and acknowledged the costs which can unexpectedly accumulate throughout the process of not only choosing merchandise but also from accepting service delivery:

I think he talked about running into the weekend and how you can only have services on Saturday; they don't usually do things on Sunday and there are extra costs involved to have it on a weekend. I think he mentioned that, and then we were running into the next week, Monday, and I don't even know who said we'd have it on Friday, but yeah, we did... I think he did give us the price on the caskets. He had a coloured folder. I remember he had a black folder with all of the caskets in it and he had the prices underneath and I do remember him saying about that, 'Have you thought about what casket you'd like? They range in price from this to this and you can get red wood oak and you can get the top of the range'. I do remember him talking about the casket. And we just went for something middle of the range, or something. I remember him saying, 'This is the most popular one here, x amount of dollars', and that was okay Yeah, so I do remember him saying about the price of the caskets, but not the other things, like the other costs involved, like transport and death certificates and funeral notices. He just said he'd take all of those and contact the [newspaper] with those. Yeah, flowers, if you wanted flowers. So yeah, it can still all rack up a lot, can't it?

7

Disease chronicity has the potential to diminish people's financial resources. Medical care expenditure involving such things as prescription drugs, equipment and transport costs to appointments, in addition to a reduced income related to caring duties, creates an economic burden for many people. This financial burden may impact upon what people are able to afford for final arrangements. Two parents in this study identified how the financial implications of caring for their two infant daughters played a key role in making decisions regarding final arrangements. The father of these two infant daughters purchased the timber to build their coffins and he dug their graves in the local cemetery. The desire to maintain control of the final arrangements, to oversee their children's well-being in death, combined with the need to curb expenditure, prompted these parents to assume many of the tasks now appropriated by funeral directors:

Like, we were poor. [My husband] left work. We were just on unemployment benefits for the whole time and we didn't want to be grieving with a six-thousand dollar debt for burying our baby. And, like I said, [my husband] will do it if he can. I'm really grateful that he could have done it because we would still be paying it off. It's bad enough that you've got to give up your job so to keep your family sort of going... Like the funeral parlours have these huge ads and it's all money. Plus it's out of your hands. We were capable. We didn't need someone to

take over. It was just simple. It wasn't like we wanted them to do brain surgery or anything like that. It was just such a simple matter we could deal with. And I think that it's good for guys to have something that they can do.

They were trying to point out that she had to be embalmed in how many hours? Twenty- four hours from death or something. Wasn't he saying something like that in a certain time?

Mmmn.

And yet [our daughters] were there for three or four days and nothing happened.

22

Maintaining control over final arrangements was considered important by the majority of participants. One participant explained how she had to ensure that the arrangements were not appropriated by a pastor of the church that her mother and father had attended.

Another participant explained how she played an active role in directing final arrangements even though her husband's body had not yet been released by the coroner. This participant liaised with the funeral director and the doctor to ensure that she maintained some agency in what transpired. In the following excerpt this participant's continued concern for her deceased husband becomes evident and her 'moral' way of knowing that an autopsy is not fair becomes apparent:

I said, 'I'm requesting that there be no autopsy. I don't want him cut up'. He said, 'I can't agree to that,' and I said, 'Why?' He said, 'Because of the circumstances, if people die at home from an unexplained illness or unexplained causes, there will need to be an autopsy'. I said to him, 'Look, I'm telling you that this person has been to hell and back in the last ten days and in various times in the last ten years he's been on death's door. I don't think it's fair for there to be an autopsy'.

15

Maintaining control was not always possible, even when arrangements had been organised prior to the person's death. The participant in the following excerpt explains how pre-planning a funeral had unanticipated outcomes. For this participant, organising final arrangements with her husband before he died 'made it a little bit easier; not a lot':

They took him away and then they rang up when my daughter went home... and said, 'Oh, we've got a bit of a problem'. Like we'd picked out the casket we wanted and I said, 'What's wrong?' They said, 'Because he's such a big man he won't fit in the bloomin' coffin!' ... So anyhow, they said, 'We've got one here, a

larger one but it's quite expensive. Much more expensive than what you chose'. And they wouldn't have time to get another one, see, being Saturday; wouldn't have time to get another one before the funeral. So I thought, 'Oh well, I suppose we'll just have to have that one,' but they let us have that one at a cheaper price. And I said, 'Well, my son wants to see him'. They said they could fit him in but he'd look all scrunched up, and I said, 'No, I don't want my son seeing him like that'. So we got that done.

13

The needs of other people were also important influences at this time. The majority of participants held the funeral of their significant other person within four days from the time of their death. Most participants explained that they made final arrangements in the post-death period being mindful of other people's needs:

And there were other people to think of, not just yourself. You had to think of the rest of your family and my grandchildren and there was sort of planning to be done because we're a big family with lots of children and grandchildren.

12

The date and time of the funeral was usually arranged to accommodate other people's needs, as demonstrated in the following passage:

We had the funeral at six in the evening, so that [my son's] friends could come too, because they all knew [my husband] and they were friendly and some friends of ours worked and then we thought they could all come, which they did, and the next day we had the cremation, just us, just the boys and I, which was nice, to keep together, so that worked well, so other people didn't have to go through that.

2

The next section of this chapter attends to people's experiences of seeing their significant other person again after they had been transported away from the home to the mortuary. The traditional parlance associated with this ceremony is known as 'viewing the deceased'. Some people regard this as an opportunity to say goodbye and others find that it enables them to place mementos such as photographs, letters and drawings in with the person before they are buried or cremated.

Viewing the Deceased Person's Body

All deceased people, other than two babies, were removed to stay in a mortuary until the funeral. The majority were removed from the home within four hours of their death.

Participants' opinions about seeing their significant other person again either before or on the actual day of the funeral were polarised. Some were definite that they wanted to; others, for a variety of reasons, decided not to. Some people found the experience stressful because they did not know what they should do, or because there was conflict about who could and who could not view the body, and others found it a concern as to how the body was presented. For some people the viewing was appreciated because it provided an opportunity to say goodbye.

For the parents of the two infant daughters who remained at home until they were buried, the viewing of their babies was considered a natural and positive experience throughout the course of the days leading up to their funerals. In the extracts below, the parents discuss how they, and others, could visit one of their infant daughters:

She sat in her little pram. We got her out of the lounge room because it was too hot. We put her in her pram.

We put her in the laundry.

Yeah, she sat out there for a couple of days and I just kept visiting her all the time.

[Our son] kept visiting her all the time and everyone who visited, we let them see her.

If they wanted to.

Yes, of course, and most people did and it was really good for them; to go out and see her and say goodbye. 22

For some people, there was no intention of ever seeing the person's body again once they had left the home:

No. No. I wasn't interested in doing that at all and neither were the kids. 14

Several participants explained that the decision not to have a viewing was based on previous experience. One of these participants speaks of the lost opportunity with regret:

... they said, 'Do you want to see the body?' and I hadn't had experience of that before because my mother hadn't, she was still alive at the time and I wasn't there for my father's death and I said, 'No, I said goodbye to him at [home]'. But I know if I had gone to see him, he'd be looking much more relaxed and he wouldn't have been looking like this poor sick ravaged little face, because he was not a big man. So I saw him really when he was suffused and cold, and rigor was setting in. I didn't see him when he was beautifully prepared, so that was my last physical memory of how he was.

11

Some participants explained how the issue of viewing the body was disturbing. In the following case, a participant explains how she was unsure what decision to make;

The next horrendous thing was when they said, 'Do you want us to have the coffin open or do you want it closed?' And I thought, 'Why would we leave it open? Why won't we just have it closed and have it in that room and when we all arrive, it will be there?' I knew they were waiting for me to say something. I was sitting there thinking and all these awful thoughts were going through your head. If it's closed, it's absolutely final. There's no opportunity for it to be opened. So I said, 'Well, leave it open but it may be of no value. We may not want to view the body'.

15

Participants understood that other family members had different views regarding a viewing and most were not against allowing other significant people to see the person if they wanted to. This way of thinking is encapsulated in the following excerpt taken from a participant's narrative about her husband's death:

... two of my daughters did who came from the mainland and when they got here, the funeral director said they could see him the next day. They didn't know whether to or not and I said, 'Look, it's up to you. I went to see my father and wished I never had. It's up to you,' and they went and I think they were both a bit sorry, one more than the other, afterwards. But I remember seeing my father and it wasn't him. The soul has gone; no point. I wished I hadn't done it. But anyway, you have to let people make up their own mind. My son and daughter who were with me when he died, they didn't want to. The other two did, who came from the mainland. I can't bear that word closure but I could understand what was happening in their lives.

20

Another reason why people found the viewing disturbing was the conflict that operated between different family members. Spouses and parents of unmarried children had greater agency in controlling the viewing of their deceased person in contrast to other relationships in this study. Siblings of the deceased person or parents of adult children

who had a partner were not always invited nor permitted to view the person's body, despite sometimes having played a primary role in their care. This finding is evident in the following quotation taken from a participant's narrative about her sister:

And [her husband] wouldn't let anyone go and see her once she was in the coffin, so I was really glad I had all that time with her at home beforehand. 26

In several instances when participants were allowed to visit their deceased significant other person, their expectations of how the person would be presented were challenged, as demonstrated in the following example:

... her husband wanted her glasses back on and I didn't like that. I didn't like to see her in a coffin with her glasses on but he didn't think it looked like [his wife] without them, so that was another thing that didn't seem right to me; lying there with your glasses on when you're dead. I couldn't see the point in that. But I didn't argue about that... 12

Viewing their deceased significant other person enabled participants the opportunity to either 'say goodbye', or to give an offering imbued with meaning. The following example illustrates how participants returned to their significant other person with particular items. This example operates in contrast to the previous example, showing how items mean different things to different people:

Mum really wanted to go back and see him. She wanted to give him his glasses because she'd forgotten to put on his glasses and he'd worn them for years. She had unfinished things that she wanted to do for him. Some of my nieces and nephews had done drawings for him and things like that. They were younger. Mum wanted to go see him and give him these things and give him his glasses and I think she gave him her eternity ring. One of her rings, she put on his finger and of course there was nobody else to go with her so even though I didn't want to go, I took her. Because she wanted me to go in with her, so I did see him. I didn't stay. I just left her and I went and sat outside the curtain. 16

Seeing their significant other person again was generally regarded as a gratifying experience for the people who took the opportunity, and for several people the viewing was imbued with a spiritual dimension:

Yes, we decided we'd have a viewing before the service, and that was interesting, actually, because I think that was important for me because when I went to see him, I thought, 'That's not [my husband]; that's just his physical shell, he's gone,' and I think that did have quite a profound effect upon me because that made me realise we are more than our physical form and my son's partner said she thought exactly the same and not many people, actually we didn't tell too many people that opportunity was available, but one or two sort of came to say their goodbyes but like I say, I knew that his spirit had gone, whereas when he was still at home, I suppose because it was so recent, I didn't sort of appreciate the detachment of the spirit from the body and that to me was a significant thing to do. 3

The next section of this chapter focuses upon the funeral service by drawing attention to how people experienced this momentous day in their lives.

Attending the Funeral

This section is divided into several parts: the different features of funerals; the challenges that emerged throughout the day; and the meanings that people ascribed to life and death. The diverse nature of funerals is evident in the features described by participants. The different features included: the size; the people who attended; the venue and style of the ceremony; the different ways of recording the event; and the choice of reception.

A selection of terms that participants used to represent the size of the funeral included: 'enormous', 'very big', 'full and overflowing', 'really packed' and 'a very small group'. The people who attended the funeral were described as being 'a purely family affair', 'all her friends and all her close relatives', 'people from all different walks of life' and 'a big representation'. Several participants noted that the nurses, and in a couple of cases, the doctor who had been involved in the care of their significant other attended the funeral. Participants recalled their attendance with appreciation, as illustrated in the following comment:

A couple of the nurses even came to the funeral. I spoke at the funeral. When I stood up on the podium, I looked up and saw them back there and thought, 'Isn't that amazing!' 17

Some funerals were held in function centres, others were sanctified in churches and several were officiated in the grounds of the cemetery. Some funerals were religious with traditional rites and ceremonies, whilst others were secular with uniquely created rituals. The following two excerpts from participants' narratives demonstrate the diverse nature of funeral practices. The first example refers to a young boy's funeral held in a church:

[Our son's] friends from Camp Quality were coming from all over the State to attend the service and arrived in a forty-five seater bus. They formed a guard of honour at the church and acted as pall-bearers, but the most beautiful tribute was when they each placed a red rose in front of the casket during the service. These roses were later gathered up and presented to us, and each rose had a name tag from the presenter. The service was most beautiful and with the church full, the singing of the hymns was full of love and meaning and though there would not have been a dry eye there I know that everyone left feeling uplifted. Later at the crematorium our friends from Camp Quality again acted as pall-bearers and provided another guard of honour. Just as everyone was leaving, all those wonderful Camp Quality people sang the 'thank you' song and the first line goes like this: 'Thank you Lord for giving us [our son]' and on it goes. 27

The next example refers to the funeral of a woman held in a community centre:

Oh, it was really good. It was a celebration of [my wife's] life. There was a lot of fun in it at times; there were tears; there were a lot of people there. The place was packed and we announced in the paper that people didn't need to wear formal clothes, so people just turned up like we are. Then we had a segment where anybody who wanted to could say something if they wanted to and several people stood up and said things. In a couple of them, there was a bit of humour in it. I didn't know I was going to, but I got up and I spoke. I had no idea what I was going to say but there seemed a need to do that. As the coffin was being removed, we didn't have set pall-bearers, that's what they're called, aren't they? We didn't decide beforehand who they were going to be. We just invited anyone who wanted to help, so there'd be someone holding the coffin and someone holding them and so on, and we all moved outside and the song that was played, [my wife] chose, and for that part it was called, 'Life is a celebration'. 25

Some people explained that the funeral was 'private' whilst others said that it was 'a public' affair. The parents of two infant daughters explained that they had a public funeral for their first daughter and for their second daughter they decided to change the organisation of her funeral on the basis of the wisdom they gained through prior experience.

... and then we had the service after she was buried. It was backwards, but, oh well. It's a very private thing. You don't know it really until that body is going down into the ground that you don't want a lot of people there. You just want to do your private thing really...

22

Some people mentioned that photographs were taken and others provided condolence books for people to write in, providing a written record of who attended the ceremony. Several participants explained how they video-recorded the funeral service so that people who could not attend would have the opportunity to see the service, as well as offering a means to view it again some time later:

And I've got it on video. I had to for his sisters. I thought I had to and I'm so glad I did... I think it's important because it's like you're in a daze. You really are. I had it done mainly so that I could send it to his sisters but then I thought, 'No, I'd like to be able to see it myself' and I don't look at it often but every now and again, I say, 'Oh, I'd like another look'.

23

More than three-quarters of participants explained how they invited people after the funeral to join them, to honour the person who had died and to connect with others, while alternatively some people chose to be alone. When people gathered together they engaged in eating and drinking, looking at photographs, offering their condolences and reminiscing:

... because everyone came back ... It was unbelievable... It was good because they all had something to say. They all said, 'Remember the time,' and 'Remember this.' One of the council blokes said, 'Remember the time he was half full and he was driving home and he drove through that bloke's front fence and knocked the fish pond over,' [laughing] 'and we had to get the council trucks to pull him out'. Oh dear! The stories they came up with and the things that he did. That was good. It was good in the sense that you laughed after the event. It wasn't a sombre thing; everyone was there; sad stories and the rest of it. It was all the laughs and all the things that he did.

21

The site of the gathering varied. For convenience sake, some people decided to offer refreshments at the site of the service, as demonstrated in the following excerpt describing a situation in which many people attended from interstate:

Then we had tea and sandwiches, sort of thing, afterwards because people came down for the day and they were going back so I couldn't try to move all these people out of town to another location, so we just did that there. 17

Some people decided to personally cater and in several instances members of the broader support network assisted with helping to organise the refreshments. One participant explained that her cousin organised an 'afternoon tea for a very small group of us'. While the experience of coming together to celebrate the life and mourn the loss was in most cases regarded as gratifying, some participants also spoke of the fortitude it required from them:

People are very kind though, 'cos they bought stuff and it was sort of like looking through photograph albums and the boys had all their friends, and so it was a case of you've just got to get through another day. 2

The prior experience of having people return to their house after their first daughter's funeral, guided two parents in their decision not to invite people back to their house after the death of the second daughter:

Yeah, because we didn't want visitors after it because we had the benefit of [our first daughter's] death to know that people just all pile in and stayed and drank and laughed and discussed their lives and we were sitting in our own lounge room like prisoners thinking, 'God, we're so tired, just go'. The minister at the second funeral said, 'Leave [us] alone'. [laughing] 22

While it was evident that funerals required significant planning, many participants explained that the day was marked by a number of challenges and unexpected events. For the majority of these participants, upsets, mistakes, frustrations or conflict between different family members arose, as demonstrated in the following four examples:

... that was really awful because my Mum didn't get to go, poor darling; she fainted on the steps and had to go home and lay down and she was just exhausted. I don't know if she actually fainted but she nearly fainted and someone had to take her home. It was all pretty dramatic. 7

So the day of the funeral, we gets our little leaflet; had the name spelt wrong. Half way through the service, a song we'd sort of chosen; it wouldn't go properly. I don't know if there was a scratch on the CD or what...my daughter was real angry because she likes things to be just right, so that didn't go off real well, really 13

The priest came .. He did mess the funeral service up a bit ... He came up and we talked all about what we wanted the service to be ... the priest forgot all about that bit. He had a captured audience and it was awful ... He was naughty because nothing came out as we had planned. That upset me because this had been going on for months. The church had been with us. I wanted it to be a celebration of his faith growing and his life and everything else. Anyway, that was that ... That was the funeral. 20

So [my brother] was involved in the money stuff and basic arrangements but didn't want to know about stuff like music and that sort of palaver; didn't want to be involved. 'Oh, I'll just leave it to you girls,' and then he wasn't happy afterwards, you could tell. He wasn't impressed with what we did. 24

Four participants in the study described how conflict occurred on the day of the funeral. In the following example, a participant explains how the day of the funeral marked dissension between herself and the family of her deceased husband. This excerpt clearly depicts the hostility and grief which has the potential to surface when people congregate for a funeral:

[My husband]'s younger brother, who is the same age as I am, took over. We had no money. He paid for the funeral and I remember just the day of the funeral being totally alienated from the rest of the family. 11

Being able to satisfy all stakeholders' needs and desires was a challenge and sometimes considered an impossible endeavour. One participant described the difficulty of pleasing all the different stakeholders involved in her mother's final arrangements:

I still don't feel like some of Mum's wishes were carried out because my older brother and sister were trying to please everyone, like Grandpa wanted to have a big funeral, like a slap-up sandwiches after; and Mum only wanted private, she didn't want people, just like she wanted to die privately. She wanted a private funeral so we didn't know what to do. She didn't want a death notice in the paper until after she'd been cremated. [My sister] and [brother] put it in, and then we had a celebration of her life or whatever they call it at [a funeral centre] but we actually sort of compromised and had a private service at [the church] which is the church at [a place] which is where all our relatives are... 8

Unexpected events, however, were not always perceived as negative. Two participants explained how unanticipated events that transpired on the day had positive outcomes:

... a well known person in [-], he organised this and I didn't know about this until we got there ... [he] got up and did the poem, you know, and then bless me heart if he didn't do 'The End of the Watch.' Well, didn't that sort the brave ones from the others! That just absolutely did everybody in. Oh, it was just wonderful! 23

... the grandchildren, of which we've got four; I was told that they were going to wheel the coffin out to the hearse and I nearly dropped dead when these kids picked the bloody coffin up and walked! It still haunts me that they carried him but anyway, they staggered and [my granddaughter] said she got a couple of blisters on her hand just going out because it was uphill, out the back of [-] there. But anyway, they did it. I really believe that in so doing — this might sound like bullshit — but somehow or other, it forged a bond. 14

Funerals were very significant to people and offered people the opportunity to put the person's life into a meaningful context. A general belief amongst participants was that the funeral offered a means to celebrate the life and mourn the loss of the deceased person. A fifth of the participants explained how the funeral offered a way of celebrating the deceased person's life:

It was a celebration of a young life. I think I spoke of her childhood and of her battle with leukaemia; her devotion to her family and her family's devotion to her. I read some very special pieces that [she] had given to her Mum about how special her Mum was. I read those. There was a letter that had been sent from Pete Murray, who is the singer ... who had visited [her] in [hospital] when she had the bone marrow transplant; he had visited [her] and sang to her. He had sent over a beautiful letter to the family and I read that to everybody, so it was like, as I say, a celebration of a very young life... one part of her life that I knew, a very quiet shy girl to her friends talking about her nights out on the town, so that was very special. Her boss who, when [she] had worked at the [-] club in [-]; he spoke of her work there at the club and of her devotion to the Hawthorn footy club and he put his footy scarf on [her] coffin. And her cousin, who was thirteen, spoke beautifully ... 6

Another participant explained how the funeral offered a means to know her father in a different light, thereby expanding her perception of him. Some participants explained how the funeral service signalled an 'existence transition' from life to death, thereby presenting the reality of the significant other person's death and serving the purpose of disposing of the physical body. This is described in the following section.

Disposing of the Deceased Person's Body

Three aspects of disposing of the deceased person's body are evident in people's narratives: making the decision whether to bury or cremate; the influences which help determine the type of body disposal; and the witnessing of the event. The main decision that people had to make regarding body disposal was whether to bury or cremate. In some instances people had decided in the years before their life limiting illness which style of body disposition they wanted:

That was sorted out many years ago. 23

Many people had strong convictions which type of body disposal they preferred:

Dad had clearly told Mum that he didn't want to be buried; he preferred to be cremated. 16

People's decision making was influenced by religious beliefs, personal beliefs, finances and significant other people's opinions:

I said, 'I'll sprinkle you at sea' and he said, 'I don't care what you do with me then. You don't have to go to all that trouble. Stick me on the garden or something' He believed in recycling, very much ... 23

Some participants explained that the type of body disposition other family members had chosen influenced their decision making:

... he wanted to be cremated because his mum had been cremated... 10

Whereas some participants accompanied their significant other person to the site of their body disposition, others explained that they did not attend the burial or the cremation:

I can just remember them taking his coffin and him being cremated, really, like, we didn't actually go to the crematorium. I can just remember thinking, 'Oh, this is what happens next', kind of thing; the reality of him getting incinerated and how that all works. 5

Another participant explained how she found attending the gravesite a distressing experience:

I can remember looking down this deep, deep hole and thinking 'My God.' That was pretty traumatic. They gave us a chair each to sit close by and actually I was a bit of a coward. I didn't go afterwards to where they wanted to have the thing. I just wanted to come home and sit ... 2

One participant explained how the issue of body disposal had to be negotiated between different family members.

My brother didn't want her buried for three days afterwards for some reason or other; I don't know why; he never really said why. It would be some sort of thing he has read somewhere ... my sister was a bit upset about that, but we just got around it.

4

The disposal of a person's body is closely associated with matters relating to a person's final resting place, as covered in the following section.

Deciding upon a Final Resting Place

Several features are evident around the issue of deciding upon a final resting place, including: where to locate the deceased person's remains; when to engage in the rite; and unexpected outcomes from decision making. The final resting place was discussed by more than half of the research participants in consultation with the person who was dying, sometimes in the years before being diagnosed with a life limiting illness:

... he had expressed the wish some time ago that [his ashes] be put into [a park]. So we had them organised there. This was probably even before he got terminally ill.

14

People often had strong convictions about where they wanted their remains:

[My wife] asked for her ashes to be put into the wall at the [-] cemetery... And I said to her I thought that would be nice if there was a little bush or little tree and we'd put a little stone under it and she said, 'No'. She wanted it in the wall because if at any time when it's my turn to go, there'll be no-one around to look after it.

9

One participant in the study described how her dying husband asked her to honour her promise to him that she would bury him on their property. Her family regarded his request as manipulative:

... he said, 'You haven't forgotten your promise to me?' and that was to have him buried. He was Irish and Catholic and superstitious and all that. He said, 'I just want to be here and I want to be near you,' and that caused a lot of trouble too because everybody in my family said that was control. That was cruel. That was going to affect selling the property and he wanted to keep the emotional stranglehold on me long after he died. But at the time I didn't really see that as a problem. So I went and got the grave organised. It had to be eight feet long and

twelve feet wide; enough for about six people and it had to be so far from the water courses and all of that.

11

Honouring the promise to a significant other person can require support from a number of people, as illustrated in the following extract:

We talked about where our ashes were going to be scattered. We picked a place we loved up on the edge of the bush. It's a stupid thing to worry about. We were talking about it this morning but it's a whole lovely vista. It's up on a hill we loved and he said, 'I'll only do it if you do it,' and I said, 'Yes. I don't want to have a burial'. I said to my son living up there, 'Well, if you ever sell the place, it's got to be in the contract. It's got to be scattered up there because I promised [your father] I would do that'.

20

Some people organised their niche or their plots in a cemetery so that family members could remain together in their after life:

.. we bought him a spot nearly where he sat and it's a double one, so my Mum has one as well and next to them, my sister bought one; they had a real big cash up that time at [the cemetery] and then next to my sister, [my partner] and I bought one, a double one as well, so they're all in a row together, so there's Dad and then there's two reserved. [My partner] laughs about it because we were only talking about it at [work] the other day; land owners that we are! [laughing] Only plot of land [my partner] thinks he'll ever own in his life; he reckons the value's tripled since he's bought it! [laughing] He said it's the best bit of land he's ever bought. 'Cos he only goes a couple of times a year and I say, "Are you coming up to Dad?" and he says, 'Oh, I better check out how my land's going I suppose. Check my plot out and make sure everything's alright. Give it a valuation. Better give it a look'. So we laugh about it.

7

The parents of two infant daughters who died, placed their graves alongside one another:

And she's up there alongside the other little girl.

Yeah, so they're up there together.

22

Whereas burial transpired shortly after the funeral service, people's ashes were most commonly scattered in the months following their cremation, illustrating how final

arrangements can continue for weeks, months and, in some instances, years after a person's death:

I think that was a few months later and then the three of us went up with somebody from the funeral service and just had our little ceremony placing the ashes together. 3

Some people explained that they still have the ashes of their significant other person at home because their intention is to scatter them with other members of the family when they die:

He didn't want his ashes stored anywhere, so Mum has his ashes at home so that when her time comes, we'll spread their ashes together. 16

Four participants in the study explained that the ashes of their significant other person were divided and located at separate sites:

Mine will be there next door to him but I reserved a few of them and the granddaughter; we only had the one granddaughter and she and I went up to the shack at the [-] because he loved being up at the shack. One windy day we took some of them up there and scattered them at the shack. [My granddaughter] said, 'I'll grow well because they blew all over me'. 14

Some people in the study explained how unexpected outcomes arose from the decision making concerning the final resting place. In the following excerpt, one participant explains how she could not deposit the entire remains from her husband's cremation:

I thought all the ashes would be placed at the cemetery so it was a bit of a shock when I found I had to bring some of them home with me. Well, you see, I had no idea that I'd even have these ashes. I thought they'd all be down there, so I've often sort of said to my daughter, 'I don't really know what to do with them because if anything happens to me,' well, she doesn't want them. I said, 'Later on we might even go down and out the back up [at a place] where; a spot out there where we used to go fishing and up the bush; he loved the bush; perhaps we might scatter them there'. I don't know... I've got them in the bedroom in an urn placed next to his photo. 13

Another participant spoke of how the scattering of her mother's ashes did not proceed the way she had anticipated:

... we scattered her ashes out through the headlands, but it was sort of a bit of a joke, really, because the kids wanted to throw the rose petals up and it was an awful day, raining and windy and Grandpa was sitting downstairs with all the diesel fumes around him. I was beside him and others were up talking to the pilot or whatever they call him, and he started to throw up in the garbage bin and I sort of went upstairs because I couldn't cope with it. We had a piper. One of our friends plays the bagpipes and he was going to do 'Amazing Grace' and my brother read a few words out of the Bible. It was all going to be done very properly. I'm sure all this was Mum's anger. You know, the whole thing just went bum up. Grandpa vomiting and then after me sitting down there with him in the vomit and the diesel fumes, I started throwing up over the side and the wind was so strong that as we were trying to throw the ashes out, my brother is trying to read and the rain is pouring down and the piper's playing. You know, it was just get it over and done with as quickly as possible by this stage and all the ashes blew back all over us and because we were wet they all stuck to us. [My sister] said, 'Oh, Mum's angry! She's really angry'. And afterwards when we came into shore we were still wet, you know, and we all met up with the other relatives in the afternoon to have a counter meal at [-] and I remember walking up the stairs with [my brother] and [he] looked at me, sort of brushing this stuff off and he said, 'Oh, Mum always did like a good counter meal. She came with us.' ... So that was the only humorous thing about the whole thing, but it was a funny day. It was an awful day, but looking back on it, it was a funny day.

8

The final place of rest has been a source of concern for five participants who have found that the distance between their home and the deceased person's final resting place prevents them from visiting:

I just wish I could drive myself there. I was only saying the other day, I don't know whether we should have made the decision or not; say, it's his birthday or things like that; I can't go, or not very often. I can go sometimes but as I say, my daughter's busy. She works full-time. She's got two young children. I can't expect her ... so it's nearly twelve months since I've been down there.

13

Several participants explained that the type of body disposal for their significant other person had been confirmed but the decision making surrounding where to deposit the remains had not been made:

She said she wanted to be cremated, but she left in a quandary about what to do with her ashes, so we've still got them. I'm starting to think about what to do with them. They've been sitting in a cupboard at home in the same room as she died.

She didn't want them spread around where we lived because she said that the place would probably get sold at some stage and she wanted them to be put somewhere we could go and visit them. I've talked to the four children about it and to her mother who is still alive about whether to put them in an urn of some sort, or keep them and rotate them around between each house as we felt comfortable with, or whoever, to place them in a cemetery facility. We haven't finalised it yet; sort of slowly moving towards it. 25

The majority of people in this study explained that they still return to the final resting place of their significant other person:

I go up there sometimes. It's a fair hike. It's nearly an hour's drive and we go up, my dog and I. But not all the times I'd like to and I tried to go up every wedding anniversary and birthday, but I don't. I think you can send your thoughts there. The time will come when I can't go at all. But I do love it. It's a place I absolutely love. I'd sit there just quietly and there's this lovely vista in front. You can see almost the whole property and it's just beautiful and it's sort of peaceful and I'll never regret doing that. I know that he felt as good as he could when he had all that settled and he knew what was going to happen. 20

The findings from this study suggest that care for the deceased person continues throughout bereavement, demonstrated by such actions as organising the final resting place, which can happen months after the person has died. In the next section of this chapter, the changes that people experienced as a consequence of being bereaved are highlighted, showing how death impacts upon people's lives when they know death deeply.

Knowing Death Deeply

The category of knowing death deeply attends to the wisdom gained from having lived the experience of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness. Participants were united in their belief that support was crucial. One participant claims:

Ask questions of all the health professionals on the care team. They should have lots of information and resources to help you. They don't always think to tell you or offer suggestions ... if possible take friends and neighbours and other relatives up on their offers of assistance – they want to help usually in practical ways that

can take some of the load off you ... Don't hurry the arrangements – you need time to plan and go through the process so you can be satisfied everything is done well and how you and your family want it done. 18

Participants explained that the death of their significant other person transformed their lives and generated new understandings. This changed perspective is succinctly expressed by the parents of two infant daughters who died:

And we're different, aren't we?

Oh, absolutely.

We're changed people. 22

The complex and enigmatic nature of people's experiences are provided in the following two comments which describe the confluence of opposite concepts:

... for me it was an experience of sadness but one [also] of beauty. 6

... it was probably the best family time I've had since I was a child, but the worst. 8

The difficulty in being able to adequately portray the depth and the essence of the experience by means of language is encapsulated in the following comment:

It's not anything you can really explain properly to anyone. 2

People used words such as 'awful', 'depressing', 'sad' and 'horrendous' to depict their experience but they also regarded it as 'rewarding' and considered it to be 'the right thing' and 'the best thing to do.' People also described their experience as 'the hardest thing I've ever done', 'an honour', 'the ultimate care you could give someone,' 'great thing to be able to do', and 'an amazing, wonderful experience'. Some participants considered themselves to be 'lucky' or 'fortunate' to have shared this journey with their significant other person. More than half of the participants also spoke about their involvement as being a 'privilege' and 'an honour':

I've never regretted for a moment doing it ... it's just a privilege, actually; that's how I see it, and I'm just thankful that I was able and strong enough to do it for her. 4

One participant describes the experience as having a lasting impact':

I think it's just not in your face all the time like it is when it's fresh, but once you start talking about it, it is still very sad emotionally and I can't talk about it without feeling a great sense of loss, really. 4

All but two participants explained that they were pleased that the person had died at home. Those who were unsure that home was the preferred place explained that their significant other person died at home because they were simply too sick to be moved elsewhere. Being pleased with having the person's death at home involved knowing that the wishes of the significant other person were honoured. It also meant that people's feelings of guilt could be appeased:

The only thing I can say, Marg, is, that it is a very, very satisfying thing to have them at home and to have them with you and it's the last thing you can do for them. I think it appeases a lot of your guilt feelings ... I think if you've got them at home and you can look after them to the best of your ability, you've got that to draw on. You can think, 'Well, I did that. I was there for them up until the end'. You weren't one step removed from it. 21

Many participants realised that their experience gave them new insights into the reality of death. The mystery and fear was removed enabling participants to accept death as a 'natural' or 'normal' part of life. Witnessing the death and final arrangements of a significant other person rather than perceiving it from a distance meant that people could speak from a place of deep knowing:

I feel that it has removed from me the mystery of death and dying which is comforting ... everything just seemed to be a natural thing to do, it's just given me a healthy acceptance of death and dying and I don't feel frightened at all. It's removed the mystery. And I think this is perhaps what is missing from our society because we don't see the process, we don't know what happens. What we see on TV and in the films and so on, somebody dies, but it's not really real. 3

One participant made mention of the unknown elements associated with death, showing how it is impossible to always control or shape the environment in which death occurs:

I mean the death is expected but the unexpected is all those other things that come; all those peripheral things that had to be taken care of. 15

Participants were very clear about how grief operates and how the lived reality is often different to how it is conceptualised in the wider community:

I don't know if people don't know what to say or they don't know how to say it or they don't want to get involved but I think a lot of these people in these positions where they're dealing with grieving people should deal with them in a compassionate, kind way; not to dismiss them. They still belong to somebody; that person belongs to somebody. 21

The findings from this study show that the event of death does not erase the relationship of being a child, parent, sibling, partner or friend, as shown in the following quotation:

... you know, Marg, death doesn't end a relationship. 24

The influence of the deceased person is evident in the following two quotations, showing how significant the relationship is beyond death:

... sometimes I think if I've got a particular situation that I've got concerns about, I'll say, 'Come on, give us some help here'. 3

You know, I still now, like, the problems happening, think, 'Oh God, Mum, where are you?' 8

In the next excerpt, a participant explains how her daughter features in her life every day and how she intends to maintain the connection with her in the after-life:

She made me a photo frame with fairies and for my birthday she gave me a tiny little parcel with a card. It sits beside my bed. [My daughter] said it would be the last thing I'd see at night and the first thing I'd see in the morning. We changed our bed awhile ago; got a new bed, but she still sits there. [My husband] knows when I die that the box comes in the coffin with me. He knows that. It's silly what you keep, isn't it, but they're special memories. 19

The majority of participants explained that their deceased significant other person still features in their thoughts or their conversations, showing a continuing bond with the deceased person. The following four quotations illustrate the bond that people have maintained:

I like to say things like, 'Dad would have liked that,' or 'He would have done this'. Keep mentioning him. I think some people find that difficult. I don't know if maybe they find it confronting or something; like, you shouldn't say it. But I like to do that because it's like you keep him close; like he's still part of my life. 16

Oh yes, we talk about her a lot. We've never stopped talking about her really... 12

I think of Dad all the time; not so much every day now but at least every week and there's something that will remind me; like I'll see an old grey haired man wandering around. Like, I still feel he's here; he's in my heart, kind of thing, for sure. 5

They're there all the time and they continue to be there regardless of if they've gone yesterday or they've gone twenty years ago. They are still there. They are still part of you and they will never be anything but that. 21

Participants also explained how other people help to maintain the memory of their deceased significant other person, either through personal correspondence or particular comments made by other people:

[My grandson] only said to me recently when he was up last; he said, 'Grandma, do you still miss Grandpa?' And I said, 'Oh, yes, really badly,' and he said, 'Oh, so do I'... 23

Concluding Comments to Stage 4

There is much to be done in the period following a person's death. A wide variety of options will often make the decision making process difficult and the demands are amplified when financial and legal pressures enter the arena. Coping with exhaustion and having little if any prior experience managing final arrangements will add to making this time a potentially stressful one. These matters are usually done alongside the scrutiny of others, such as family members, friends or service providers, who may in some instances convey their judgement or impose their own values and expectations. What people may also find is a disparity between their own lived experience and the imagined reality perceived by those who have yet to encounter death and final arrangements on a personal level. Despite these challenges, people still manage to find different parts of their experience gratifying. This gives rise to the belief that these

experiences are imbued with meaning and serve a purpose not only for the deceased but also for the person who participates in the arrangements. Despite the anguish and sorrow that people encounter through their grief, many maintain that their experience has offered insights and wisdom from a deeper understanding of death. Death has the potential to transform people's lives. For many the deceased will maintain a presence, showing that the relationship continues beyond death.

Stage 5: Explication

In explication a more complete apprehension of the key ingredients is discovered. Additional angles, textures, and features are articulated: refinements and corrections are made. Ultimately, a comprehensive depiction of the core or dominant themes are developed ... The researcher explicates the major components of the phenomenon in detail, and is now ready to put them together into a whole experience (Moustakas 1990, p. 31).

This section of the thesis reports the explication stage of the enquiry. An explication of the data details a deeper analysis of the findings brought about through the processes of 'reflecting, exploring, sifting and elucidating' (Douglass & Moustakas 1985, p. 40). In Chapter 10 of the explication stage I examine how my findings converge with and diverge from the current research literature. Throughout this chapter, I demonstrate how the care provided during this period is intensive. Fatigue, change and incessant demands make this a challenging and difficult time. I claim that people's care continues beyond the time of death, extending in some instances for the lifetime of the bereaved. I draw attention to the positive outcomes of care by highlighting people's strengths, resources and capacities that evolve throughout this time and propose that these qualities may be overlooked because of the prevailing focus upon the risks and problematic behaviours that have been identified during bereavement. I also highlight the need for appropriate support.

Chapter 10: Discussion

Introduction to the Chapter

In this chapter I describe how the findings of my research support and challenge the research literature on attending to the death and final arrangements of a person who died at home from a life limiting illness. This chapter is divided into several sections, using the three temporal periods of 'Before the Death'; 'At the Time of Death' and 'After the Death' to discuss the findings.

Before the Death

Intensive Care

The findings from this study support the research which shows that in contemporary western society dying from a life limiting illness often happens over a period of months and even years (Bern-Klug, Gessert & Forbes 2001; Field 1996; Kellehear 2007b). This research also showed how the diagnosis may take some time after symptoms of a life limiting illness have been detected. When a diagnosis was given, participants found the news distressing but appreciated being told the reality by their doctor or medical specialist. Having a diagnosis meant that some people wanted to know how much time remained, with greater focus given to when the death would occur, particularly in the days leading up to the death.

The decision to die at home happened in a variety of ways: without discussion; in discussion with people other than the person with the life limiting illness and in open discussion with many different stakeholders. These findings are comparable with the research of Stajduhar and Davies (2005) which used the words 'uninformed', 'indifferent' and 'negotiated' for the different categories of family members' decision making for palliative care at home. Their study (2005) identified several reasons as to

why people decide to die at home: honouring a promise; wanting a normal family life; and avoiding negative encounters with institutional care. These reasons were also highlighted by the participants in this study; however, a range of other incentives emerged, including: not wanting to relocate the dying person because she/he was too ill to be moved; providing the dying person with a sense of identity and personhood; exercising control in the environment through notions of security and privacy; enabling close proximity to attend to the person's needs; and allowing the person to stay in the place that they loved.

Living in contemporary western society means that most people expect a 'good death' by which is meant having pain and other symptoms appropriately managed and adequately controlled (Meyer 1998). This expectation is promoted by the philosophical tenets of Palliative Care Australia (2005). In this study, participants aspired to provide a good death for their close other person, which involved making a concerted effort to assist in alleviating their suffering. The findings from this study are consistent with research that identifies pain and symptom management as a predominant concern of carers in the final days and hours leading up to the death (Addington-Hall & McCarthy 1995; Hallenbeck 2005; Hanson, Danis & Garrett 1997; Hinton 1994; Sankar 1993; Vachon 1998; Ventafridda et al. 1990), offering insight to the challenges confronting people providing end of life care at home.

When pain and other symptoms became problematic and the mental and physical exhaustion from care-giving persisted, some people doubted that they could continue providing appropriate care for their close other person. It was during these times that people considered relocating the dying person to a hospice or acute care setting where symptoms could be managed by healthcare workers with expert knowledge of medical and pharmaceutical technologies. These findings are similar to other studies (Beccaro et al. 2006; Higginson & Sen-Gupta 2000; Hinton 1994; Tang 2002; Townsend, Frank & Fermont et al. 1990), highlighting how people's preference for place of death may change over time. People also explained the difficulty in being able to accurately know when life would end, causing concern to many participants as to how much longer they could manage their feelings of exhaustion and distress. Participants in this study realised that caring for their close other person took a toll upon their well-being, particularly in terms

of physical and mental exhaustion (Grbich, Parker & Maddocks 2001) but they did not regret their concerted efforts providing care at home. They did, however, find other people's criticism and lack of faith in their capacity to provide care at home unhelpful and offensive.

Appropriate Support

This study has identified the arduous and unrelenting care needed to enable a person to die at home. This thesis argues, therefore, that the journey is a considerable undertaking, requiring a community-focussed approach to facilitate this preferred option of care. The support from friends and extended family members, community nurses, doctors and medical specialists, as well as access to specialised equipment, was identified as important for people dying in the community. One person in this study did not receive any community support after being inappropriately discharged from hospital. The husband of this participant died at home without access to community services or information and the event of death was described as 'a most horrific, obscene passing'. Roy (2000) and Seale (1995) have highlighted how dying at home without community resources provides no guarantee of dying with dignity. This study supports their argument and claims that a death at home from a life limiting illness requires appropriate and competent discharge processes from hospitals. It is also necessary to understand that a death at home should not be regarded as a 'gold standard' for everyone in the community (Donnelly, Michael & Donnelly 2006). Certain diseases and their symptoms may render the task extremely difficult for people to manage at home. Some carers in this study also had their own health issues to manage, which makes the prospect of enabling someone with a life limiting illness to die at home a very difficult undertaking, especially without appropriate support.

Positive Outcomes

The research literature focusing on caring for a dying person has consistently highlighted how the provision of informal care significantly contributes to the diminishment of people's economic, physical, mental, social and emotional wellbeing (Kristjanson &

Aoun 2004; Mastrian, Ritter & Deimling 1996; Palliative Care Australia 2004; Stajduhar & Davies 1998). Compelling evidence from the biomedical field shows that many people who care for someone with a life limiting illness will enter the period of bereavement with identified risks and potential problem behaviours, thereby raising their levels of morbidity (Kreicbergs 2005; Kristjanson & Aoun 2004; Latham & Prigerson 2004; Prigerson & Maciejewski 2005-2006). Grbich, Parker and Maddocks (2001, p. 35) claim that the research literature places little emphasis on the positive emotions and coping strategies of caregivers of family members with a terminal cancer, and Hudson (2004, p. 58) cautions that this dominant focus on the negative aspects of caring for a dying person at home will perpetuate inherent risks of 'pathologising care giving and inadvertently socialising caregivers to expect burden'. This thesis does not intend to minimise the risks and distress experienced by people who care for a close other person dying in the site of the home. This thesis does, however, diverge from the greater part of the research literature by shifting the dominant focus away from the negative outcomes in order to illuminate the potentials and opportunities inherent in caring for a person dying at home. Participants in this study did extraordinary things, such as moving out of their own home to care for another person, committing to a journey described by some people as the hardest thing they have ever done and undertaking tasks which they had never before experienced. A key outcome for people was that they experienced in a very real way their capacity for compassionate love.

At the Time of Death

Several points of discussion emerged from people's experiential accounts at the time of death. These include the small supply of research attending to this specific time, the activities of watching and waiting undertaken by people caring for the person dying, the importance placed upon this particular time, the consequences of interventions, the different pathways that people encounter, and the ongoing care.

Intensive Care

Nuland (1993, p. *xvii*) notes that there is a 'vast literature on death and dying' but states that 'the details of physical deterioration have for the most part not been much stressed'; however, this study showed how such details were a considerable concern for people. Some people are unprepared for the physical reality of dying. In this study, several participants explained that their experience was unlike what they had observed in the unrealistic portrayals of the media through television or cinema depictions. It is quite probable that the portrayals of death in the entertainment media engender false expectations or perpetuate myths, such as the dying person remaining alert and articulate until the moment of death or appearing in reasonable physical shape. As well as being unprepared for the harsh reality of dying, some people said that they were surprised how they felt in response to seeing their close person's health deteriorate. Some of the participants in this study who had previously worked with people dying explained that their experiences in employment did not prepare them for the intense emotions they felt in the time surrounding the death of their close other person. The findings from this study align with those of Grbich, Parker and Maddocks (2001) and Sankar (1993) which identified people's deep anguish as they witnessed the visible and audible signs of their close other person's deterioration. Wishing for the person to die for the purpose of ceasing their suffering was a common experience amongst participants and memories of these thoughts were often permeated with feelings of guilt, which is consistent with the findings of Sinding (2003).

As time progressed, people recognised a range of physical and mental changes in their significant other person's condition which alerted them that the time of death was imminent. These changes inspired participants to gather at the death scene and to closely watch for signs of diminished breathing and fading heart beats. Having a heightened sense of awareness to determine when the moment of death might occur has been highlighted in other studies (Donnelley, Michael & Donnelley 2006; Meeker 2004; Staton, Shuy & Byock 2001; Woodhouse 2005).

People described a range of experiences relating to the duration of their close other person's dying and their behaviour in the final days and hours of life. Some people who

were conscious up until the last moment were still capable of speaking; others were delirious, sometimes unconscious, not responding to those gathered around the bedside. Two participants in this study also witnessed a paranormal event. These participants found it a challenge to explain this encounter yet recognised it as being a significant moment at the time of death. Such encounters have recently been described in the literature on death and dying (Barbato 2005; Fenwick, Lovelace & Brayne 2007), suggesting that this is an area which warrants further study. This thesis has shown how the experience at the time of death will vary for individuals, supported by Nuland (1993, p. 3) who claims:

Every life is different from any that has gone before it and so is every death. The uniqueness of each of us extends even to the way we die.

Most participants in this study explained that they did not know for how long the dying process would continue, creating a complex medley of responses, including fear, distress and physical and mental exhaustion. Studies have described the dying process as ambiguous (Bern-Klug 2004, Bern-Klug, Gessert & Forbes 2001; Kellehear 2007a; McNamara 2001), revealing how symptoms of dying can be masked by interventions for the purpose of alleviating suffering. An expectation in contemporary western society is that we can experience dying without suffering and it is clear that people's expectations of doctors to provide pain and symptom management contributes to the ambiguous nature of dying. This thesis raises the point that it is an onerous task for doctors and nurses to reasonably indicate when death will occur in light of people wanting to alleviate the perceived suffering of their close other person by means of medical intervention.

When so much of death is unknown, particularly in regards to the speculation of what happens beyond death, having the capacity to know when and where death occurred gives back to people some agency in life's final transition. Participants in this study wanted to stage a death scene which would be respectful to, and honour the life of, the person dying, thereby restricting those in attendance, keeping disturbances to a minimum, and imbuing the atmosphere with ambient qualities, sometimes using music and soft lighting. These findings are consistent with those of Staton, Shuy and Byock (2001) and Brown and Stetz (1999). When participants in this study were satisfied with the

outcomes of a person's death, they expressed a sense of comfort and relief. This did not reduce people's grief but offered solace in the knowing that their significant other person's wishes had been fulfilled, and that their death honoured their life. Participants found the time of death distressing when the scene of death did not transpire in a way which was anticipated, such as occurring in their absence, in the presence of a commotion, in association with uncontrolled suffering, or being responded to by emergency services. Kaufman (2005) and Kastenbaum and Normand (1990) have highlighted how the actual process of dying and the moment of death are often at variance with how people expect these events to transpire. Participants were disappointed because they believed that the moment did not honour the life of the person who died, or caused harm to their close other person in their final hours of life.

Appropriate Support

The findings from this study show that not all events can be controlled by the person who has a primary caring role. The capacity to manage or control life's final transition is impossible, especially given that the event has to be negotiated with a range of other people. Death has to be negotiated with many stakeholders, demonstrating what de Vries (1981, p. 1077) refers to as the 'social construction of death'. This study found that while death is an immutable fact, the way in which it transpires remains uncertain.

The interventions of those in attendance will influence how the time of death is experienced, demonstrating the way in which the time of death is influenced by a diverse array of environmental and biological factors. Grant's (1997) study of emergency services arriving to 'expected deaths' has shed light upon the need to educate families, healthcare providers and emergency response teams in the appropriate ways of dealing with an anticipated death at home. Several participants in this study described their experiences with the police, ambulance and in one case, the coroner, expressing their ongoing sadness about the unnecessary intrusion at end of life which added yet another dimension to their grief. This finding is congruent with the research literature which has established that adverse events in the last weeks of a person's life can influence people's grief responses (Hudson 2006; Staton, Shuy & Byock 2001).

Witnessing their significant other person leave the home was a distressing experience for many participants. Two parents of infant daughters decided not to entrust the care to others following their daughters' deaths, preferring to self-manage all final arrangements. Having their deceased children at home until they were buried in the local cemetery meant that these parents had time, space and privacy, — the three elements identified by Davies (2005) that have significant value to parents.

This thesis has also highlighted how few studies consider how community health providers influence the experience of people attending the death in the site of the home. Those studies which do acknowledge this particular aspect of end of life, (Beresford, Adshead & Croft 2007; Donnelly, Michael & Donnelly 2006; Parsons 2003) report that the assistance regarded by people as helpful is characterised by the qualities of compassion, respect, sensitivity and competence. This applies to doctors, nurses, social workers, chaplains and funeral directors. In this study, people appreciated calm, non-judgemental and reliable assistance, often given by someone who remained in the background and was ready to provide assistance when needed. The meaning that one participant assigned to the simple act of being offered a cup of tea by a support person immediately following her daughter's death showed the value of having appropriate, competent and context-specific support (Bern-Klug, Gessert & Forbes 2001). No platitudes, no clichés and no advice-giving were evident, showing the powerful role that 'presencing' offered one participant at end of life. Donnelley, Michael and Donnelley (2006, p. 362) explain that 'in the drama and the choreography of the moment of death, the guide seems to be in the wings giving cues', thereby avoiding 'the tyranny of specialisation'. Professional support for death and dying in the community is often provided by palliative care and hospice services. Since workers in these fields are often regarded as 'specialists,' the implication may be that only 'experts' can facilitate a 'good death'. Kellehear (2005, p. 2) recognises the dominance by the medical profession in end of life issues, and harks back to the value of social support in communities:

It is important to recognise that the history of travellers in the valley of the shadow of death is also a history of our community care and support for each other. Formal care of the dying has emerged gradually through history from that broader and longer history of community care (Kellehear 2005, p. 2).

Positive Outcomes

People hoped that they would not miss the moment of death and expressed worry that they would be absent or asleep when the moment occurred. Being present at the death was regarded as a responsibility or duty or a final gift that people could offer to their significant other person in life's final transition. Sinding's (2003, p. 162) study concurs with these findings by claiming that the 'imperatives of end of life care were underlined ... by a desire to minimise regrets, to evade both the sorrow and responsibility of failing to "do everything possible"'. Being present also meant that people did not have to imagine what transpired because witnessing the event prevented not knowing what happened. By being present, people were able to convey their expressions of love and attend to the needs of the person who was dying. In some instances, children and pets attended. These findings are congruent with other studies (Brown & Stetz 1999; Keeley 2007; Meeker 2004; Sinding 2003; Staton, Shuy & Byock 2001; Woodhouse 2005) demonstrating the importance of relationship at the end of life (Donnelley, Michael & Donnelley 2006; Keeley 2007; Sinding 2003). During this period, participants wanted to connect deeply with the person who was dying by communicating love in a variety of ways. This finding is consistent with Keeley's (2007, p. 245) study which found that the expression of love 'whatever its form – is a priority'. Grbich, Parker and Maddocks (2001, p. 35) found that carers expressed pleasure in being able to have 'the opportunity to communicate one's love and to show affection through care ... when the patient was able to respond and to appreciate this love, much of the negative emotion experienced was alleviated and the caregiver's self-worth heightened'. Being with someone as they died was regarded as a meaningful experience.

Continuing Care

While death has been identified by Rhodes and Shaw (1990, p. 40) as 'the final end point' of care-giving, some researchers (Davies 2005; Hallenbeck 2005; McGrath 2007; Pattison 2008; Quested & Rudge 2003; Sinding 2003; Weber, Ochsmann & Huber 1998) understand that care for a deceased person continues beyond the moment of death. This thesis demonstrated how caregiving continued beyond death, demonstrated by such actions as: arranging a medical certificate for cause of death; washing and dressing the

deceased person; and overseeing the removal of the deceased person away from the site of the home. While it may be argued that these actions were merely duties imposed by a decision to have a person's death situated in the home, I further argue that the attitudes invested in these tasks demonstrate an ongoing care demonstrated by the actions and attitudes of people in the way that they undertook these tasks and responsibilities. If people did not personally undertake these tasks, they expected that those to whom they entrusted the responsibility would deal sensitively and respectfully with their deceased other person, also indicating an ongoing care for the person who died.

After the Death

Intensive Care

In the time following on from the death, participants focused their attention towards final arrangements, planning, organising and participating in affairs which would pay tribute, either privately or publicly, to their close other person. Organising final arrangements in advance has been recommended (Bern Klug, Ekerdt & Wilkinson 1999) as a means to maintain control, reduce distress and prevent disappointment. The findings from this study showed how advance planning has definite benefits, such as reducing stress in early bereavement which is evidenced by the relief expressed by participants when they 'knew' what to do. However, when advance planning had been undertaken and unexpected outcomes occurred, the disappointment and regret expressed by participants in this study was significant. This thesis claims that advance planning cannot eliminate every feature which may impact upon matters relating to a person's death and no assurance can ever be guaranteed that every risk, problem or hazard can be controlled by the planning of final arrangements. This claim is supported by the research (Gamino et al. 2000) which recognises that final arrangements can occur in unintended and unforeseen ways, causing ongoing concern and anxiety to people throughout their grief journeys.

The research literature on people's experiences of self-managing final arrangements is conspicuous by its absence. Self-managing final arrangements is an alternative to

mainstream practice and was only undertaken in this study by two parents who kept control of their infant daughters until they were buried in the local cemetery. This study showed how the building of the children's coffins and the digging of their graves was regarded as a 'good' thing to do by the children's mother and father, implying that personal involvement with final arrangements may not only assist with keeping finances under control but also provide therapeutic benefits.

Appropriate Support

Researchers (Bern-Klug, Gessert & Forbes 2001) have highlighted the responsibility of healthcare workers, in particular social workers, to provide appropriate, competent and context-specific support for people attending to final arrangements. This support is in recognition of the knowledge that problematic issues arising from final arrangements (Doka 1984-1985; Gamino et al. 2000; Lensing 2001) can add to people's grief and distress in their bereavement.

Evident in this study, but lacking in the research literature, was the way in which people are treated by institutions and agencies dealing with matters of finance, superannuation and inheritance. In this study, lawyers, financiers, solicitors and government personnel, such as Centrelink officers, were often regarded as providing insensitive and incompetent service delivery. In one participant's case, her father's money was embezzled and she did not inherit what was rightfully hers. In another participant's case, her inheritance was challenged by her deceased husband's extended family, continuing for many years after his death. These experiences have the potential to negatively impact upon a person's grief journey, yet the stress and frustration caused by such factors may never receive recognition by others.

Positive Outcomes

Two key features are discernible from people's experiences in this study. These include the benefits from participating in the journey and the strengths that emerged from committing to the journey. A small yet growing number of researchers have shed light

upon the positive outcomes of caring for a dying relative (Cohen, Colantonio & Vernich 2002; Grbich, Parker & Maddocks 2001; Hudson 2004; Keeley 2007; Singer et al. 2005) as well as the positive outcomes experienced from loss (Calhoun & Tedeschi 2001; Kellehear 2007a; Hudson 2006; Moody & Arcangel 2001).

The benefits resulting from people's engagement in end of life matters include empathy, an appreciation of the value of relationships, and compassion. Kellehear (2005, p. 141) supports this claim, stating that 'greater personal sensitivity and social empathy frequently comes to those who know loss intimately'. The research literature concurs that compassion is associated with the provision of social support and pro-social behaviour (Kellehear 2005; Sprecher & Fehr 2005). Edmonds and Hooker (1992) also found from their study that in operating alongside the negative effects of grief from bereavement, was a development in people's personal growth and self-transformation.

Continuing Care

Ongoing care for a person who had died was evident in people's actions and attitudes. People's commitment to their relationship did not cease once their significant other person had been removed from the home. If the person who was dying had voiced a preference for something to be done at the funeral or with the disposal of their body and their memorialisation, participants undertook to fulfil those preferences, despite on occasions knowing that it would require considerable effort to comply with the person's wishes. Being able to honour the wishes of their close other person was regarded as a mark of respect and offered comfort and solace to people throughout their bereavement. When participants were unable to carry out final arrangements that had been chosen by their close others, or arrangements were undertaken without knowing what would have been preferred, they voiced regret or sorrow, feeling that they had fallen short of their responsibilities.

Participants were unanimous in their belief that the deceased person still played a significant role in their lives, assigning value and meaning to their relationship regardless of how long it had been since the person had died. Kellehear (2005, p. 141) explains how

‘people continue to have relationships with their dead through dreams, ambitions or actual visions of them’. Looking at photographs, reading correspondence, hanging their portrait on the wall, wearing their jewellery and positioning mementoes such as reading glasses, figurines and special awards around the house, were commonly described by participants. Accepting the responsibility of guardianship for companion animals which played a key role in the life of the deceased person was also demonstrated by participants in this study. Visiting their final resting place, maintaining their gravesite and placing flowers at their niche or gravesite on anniversaries or birthdays were activities that participants would often undertake. Participants also explained how they still continue to talk to their deceased close other, how their decisions are influenced by what the person would have thought, how they continue to feel their presence in their lives, and how they purposely maintain the position of their deceased person within family and close friend’s circles by talking about them and introducing them in conversations with people who did not know them. These practices are compatible with the ‘re-membering practices’ described by Hedtke and Winslade (2004) which pay homage to the ongoing relationship. These findings are consistent with those in the research literature (Attig 2004; Bennett & Bennett 2000; Daggett 2002; Davies 2005; Hedtke 2003; Vickio 1999), showing how the deceased continue to have membership in the lives of the living. Maintaining membership with the deceased (Attig 1996; Hedtke & Winslade 2004; Klass, Silverman & Nickman 1996; Vickio 1999) has offered bereaved people an alternative practice to the more traditional theories which campaign ‘letting go’ and ‘moving on’. The premise operating within this alternative discourse is that people’s lives can be enriched when they choose to participate in an ongoing relationship with their deceased close person.

Concluding Comments to Stage 5

This thesis goes somewhat towards expanding the empirical body of knowledge which makes sense of how people experience the death and final arrangements of a significant other person who died at home from a life limiting illness. The care that people provided was intensive, peppered with many challenges and demands from a range of stakeholders, and this care was also extensive, since it did not cease at the time of death. The care provided by participants was holistic attending to: the physical; spiritual;

emotional; and psychological needs of people for twenty four hours per day and seven days per week. In many cases, this care was provided for months, years and in some cases for more than a decade.

The need for appropriate support from others was identified, with particular emphasis placed on people's qualities. This thesis has also demonstrated that those who have companioned their close other to the end of their life in the site of the home have a rich array of strengths, capacities and resources which support them in their goals. In the following section of this thesis, known as creative synthesis, I offer a model for understanding how people experience the death and final arrangements of a significant other person who died at home from a life limiting illness.

Stage 6: Creative Synthesis

Once the researcher has mastered knowledge of the material that illuminates and explicates the question, the researcher is challenged to put the components and core themes into a creative synthesis. This usually takes the form of a narrative depiction utilising verbatim material and examples, but it may be expressed as a poem, story, drawing, painting, or by some other creative form (Moustakas 1990, pp. 32-33).

The final stage of heuristic enquiry known as creative synthesis features in Chapter 11. In this chapter, I present a model which conceptualises how I understand the lived experience of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness. I discuss the implications of this study and make recommendations for social work practice and research. I bring this thesis to a close by expressing my gratitude to the participants of this study for the lessons learnt from their lived experience.

Chapter 11: The Lived Experience of Compassionate Love at End of Life.

Introduction to the Chapter

In this chapter I argue that the spirit guiding participants' decision making at end of life is a set of experiences and responses that I have chosen to call compassionate love. I claim that compassionate love operates as five interdependent practices which enables the expression of human qualities of care. This chapter begins by defining the term *compassionate love*, followed by a description of the five practices: responsibility; concern, commitment, respect and knowing. The qualities which flow from compassionate love are also identified. I give consideration to the implications of this study and make recommendations for social work practice and research. I conclude this chapter by paying tribute to the people who shared their lived experiences for this study.

A Definition of Compassionate Love

The etymology of compassion comes from the Latin *compassio*, meaning fellow-feeling, and *compati*, to suffer with (Collins English Dictionary 1979, p. 308). Compassion is, therefore, the demonstration of mercy in the company of suffering. Kellehear (2005, p. 41) defines compassion as 'a joint journey of sharing with another' and the term *compassionate* to 'have this quality of attitude and action' (Kellehear 2005, p. 41).

In contemporary western society, the term *love* has different meanings, often used in reference to individualised and intimate relationships in which a strong attachment is evident. Frohm's (orig. pub. 1957, 1984 p. 28) theory proposed that the art of loving always involved the four essential elements of: care; responsibility; respect and knowledge, promoting the idea that love was an art because it required practice and sustained effort. My study pays tribute to Frohm, applying three of these dimensions, but

the lived experience of compassionate love in this study also involves two additional facets. I argue that compassionate love is 'a joint journey of sharing with another' (Kellehear 2005, 41) in which the practices of responsibility, concern, commitment, respect and knowing operate for the well-being of another. This claim is consistent with Sprecher and Fehr's (2005, p. 630) definition:

Compassionate love is an attitude toward other(s), either close others or strangers or all of humanity; containing feelings, cognitions and behaviours that are focused on caring, concern, tenderness and an orientation toward supporting, helping and understanding the other(s), particularly when the other(s) is (are) perceived to be suffering or in need.

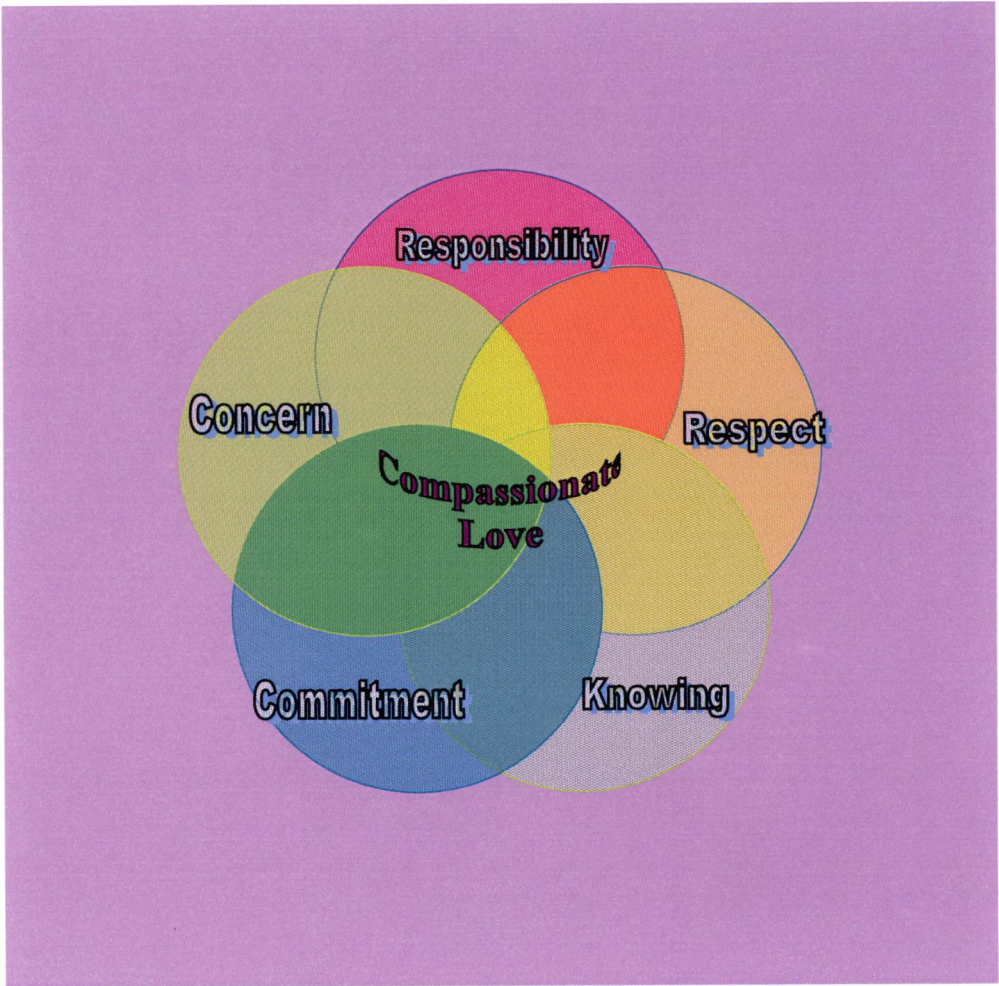
I further add that the expression of compassionate love has benefits not only for the people receiving care but also for the person providing the care, as it enables their strengths to emerge and provide a deeper understanding of life and death.

I propose that compassionate love at end of life operates as a gift and that it has been conceptualised in this way for two reasons. First through its practice, people's strengths and capacities emerge for the purpose of helping others approaching end of life and beyond. Second, by engaging in the five different practices of compassionate love, people raise awareness of their own potential. The journey that participants chose to undertake was not easy, requiring self-sacrifice amidst adversity and irreplaceable loss. The decision making was often difficult but what enabled people to stay while others could walk away was the value that people placed upon their relationship with the person who was dying. By staying, and engaging in the five practices, people's strengths emerged, showing how the gift of compassionate love provides benefits for not only those who receive the care but for those who provide the care at end of life.

At the time of death and throughout final arrangements, the five practices all operated within a context of change and uncertainty, often in the midst of fear, exhaustion, conflict and profound sadness. The findings from this study show how none of the five practices operate as a discrete entity because each demonstrates a complex interplay with one or more of the other practices. The following section of this chapter presents a model of care (Figure 5) which describes how I believe the five practices coalesce to create the gift

of compassionate love. Each practice is described, commencing with the practice of responsibility.

Figure 5: The Five Practices of Compassionate Love



Responsibility

The practice of responsibility involves five features. Having a sense of responsibility implied a significant relationship with a strong attachment. A strong attachment does not necessarily mean that the relationship was amicable. Several participants explained that they had experienced a troubled history with the person who died, but they recognised their strong attachment and made a choice, either consciously or otherwise, to become involved in the journey.

The second feature of responsibility involves recognising a significant other person's need, such as wanting to die at home, having companionship, or being cremated and having the remains located at a specific site. Sometimes these needs were articulated by the person dying. In cases where the person was too young or too ill to identify a specific need, participants assumed responsibility with the best interests in mind for their significant other person.

The third feature of responsibility involves assuming responsibility for others in addition to the person who was dying. Taking care of others was evident in cases where support was given to elderly parents, children or another member of the extended family who needed assistance. The practice of responsibility was often interpreted as a duty or an obligation and sometimes it was regarded as something which just had to be done.

The fourth feature evident in the practice of responsibility concerns the delegation of duty. In some instances, participants explained that they were given the responsibility to attend to certain tasks by other members of the support network without negotiation, such as organising the funeral. One participant was directed by hospital staff to take her husband home to die without further instructions or assistance. In both instances, people felt that the responsibility they were given was unreasonable, and created substantial stress.

The final feature of responsibility concerns the activities of planning, organising and implementing arrangements, often undertaken at a time when people felt bereft with grief and depleted of physical and mental energy. When organising was done with the significant other person's wishes in mind, people often experienced a sense of comfort and relief. Alternatively, when undertaken with the competing demands and conflicting interests of other stakeholders such as family members or service providers, people expressed anger, frustration and sorrow.

There are two aspects which are common to the different features of responsibility. The first aspect involves the demands that are inherent to this practice. For the participants, having the responsibility to make sound decisions was a considerable challenge in light of the conflict, stress and uncertainty that operated in many people's lives. The second

feature involves the comfort that the practice of responsibility offers to others and in many instances, to the person making the decisions. To have the onus of responsibility may be regarded as a hallmark of the trust assigned to another person to make sound judgments on another's behalf.

Concern

The practice of concern was demonstrated in people's attitudes and actions of caring for a significant other person. This practice was often expressed as a worry about a person's health, comfort or well-being regardless of whether they were dead or alive, indicating how care for a significant other person can continue beyond death. Other examples of people's concern included: wanting to alleviate the suffering of their significant other person; in their worry that their deceased close person might be dropped in the transfer leaving the home; and in their expression of regret in being unable to visit and maintain the gravesite or memorial plaque of their deceased close other person.

Van Manen (2002, p. 268) claims that 'care-as-worry' may 'be experienced as a complex moral-emotional relation of responsibility'. This proposal supports my claim that the five practices of compassionate love demonstrate a complex interplay with one or more of the other practices. Each participant in this study companioned their significant other person throughout all or part of their dying, in the site of the home, choosing to remain with the person in their final days of life. To have their significant other person die alone was an outcome that participants fervidly wanted to avoid, and so being with the person at the moment of death became an imperative in people's caring. To attend the death in the site of the home meant that many people had to make substantial changes in their own lifestyles. These changes in lifestyle translated into engaging with and participating in matters relating to the death and final arrangements. Primarily, it meant making a commitment to the relationship.

Commitment

The practice of commitment is demonstrated by people staying with their significant other person. In this study, the selection criteria stipulated that participants had to have attended to their significant other person's death in the site of the home. What emerged from the findings was that almost half of the participants departed their own home to live in someone else's home, either belonging to their close other person or one which enabled easy access, such as a neighbour's house. Furthermore, almost a quarter of the participants cared for their close other in a state of Australia other than Tasmania. The significance of this finding is that some people who attended to the death and final arrangements were temporarily displaced from their own home. Many of the reasons unearthed in the findings which help to explain why people decide to die at home — including notions of self- identity, familiarity, security, privacy and a feeling of being connected to a place of belonging — are precisely what people sacrificed in their own lives to enable their significant other person to die at home. Making the decision to enable a death at home is founded on the belief that the person dying is significant in the life of the other thus showing the importance of relationships at end of life.

Always operating in the practice of commitment is the action of witnessing. Witnessing is a process enabling people to perceive what becomes apparent, involving seeing and/or listening in combination with an attempt to make sense of what is happening. Witnessing is a purposeful activity, demanding a commitment to stay and wait, generally involving some expectation that there will be a change in what is currently happening. The experience of witnessing was done by participants for the purpose of being present, and when prolonged was usually accompanied by exhaustion. Witnessing involved a gamut of personal responses, such as feelings of fear, doubt, sadness, helplessness and relief.

Respect

The practice of respect was demonstrated by having a regard for a person's uniqueness or individuality. This action and attitude was evident when participants facilitated the goals or wishes that were important for their close other person, such as dressing the deceased person in the clothes that honoured who they were in life, purchasing a coffin or casket

which would have been the preference of the deceased person, or playing music at the funeral which paid tribute to them. Having respect for a close other person also signified a close relationship, as participants would speak on their behalf or defend their interests when their significant other person was no longer able to.

Knowing

The practice of knowing was demonstrated by participants through developing an intimate knowledge of their own needs and of the needs of their significant other person, sometimes greater than the knowledge that formal carers could offer. People described a gamut of emotions associated with knowing, such as uncertainty, fear, relief, joy and comfort. Living the experience provided people with a deep knowledge about matters of mortality which could not be achieved otherwise. The different ways of knowing identified by Carper (1978) and Hudson (1997), described in Chapter 4 of this thesis, were evident in participants' experiences.

Aesthetic knowledge is evident in the care provided by two parents, who used the wisdom gained through prior experience to purposely shape the course of events for their second baby daughter to die in infancy. In this instance, the parents arranged their second daughter's funeral so that a private burial of their daughter could occur before the church service. This arrangement was purposely done on the basis of knowing a preferred option of care. Personal knowledge is evident in the experience of one participant who explained that he 'just knew' that he needed to keep his wife's body at home for a certain period of time before it was transferred to the funeral directors. Another participant explained that she intuitively knew that her husband was going to die even though she was not in close proximity to him. Having faith in her way of knowing, she quickly returned to his bedside and he died in her presence. Participants also used commonsense to help them understand what was happening, as demonstrated in the instance when a participant observed a significant deterioration in her mother's condition and subsequently slept in the same room so that she could attend to her mother's needs and be present at the moment of death. Cultural sensibilities were evident in participants understanding that while their loss was shared by other members of their extended

family, the ways in which they responded were different. Moral knowledge was evident in the experience of one participant who defended her deceased husband's right not to have an autopsy, knowing that it wasn't fair to interfere with her husband's body because hospital staff had been unable to detect signs of imminent death.

In summary, this thesis argues that compassionate love was demonstrated in the actions and attitudes of five interdependent practices: responsibility, commitment, concern, respect and knowing. Responsibility involves the willingness to take on tasks for others; commitment involves taking on tasks for a period of time for as long as is required; concern involves taking on tasks with care; respect involves taking on tasks in ways that honour another person, and knowing involves taking on tasks in purposeful ways.

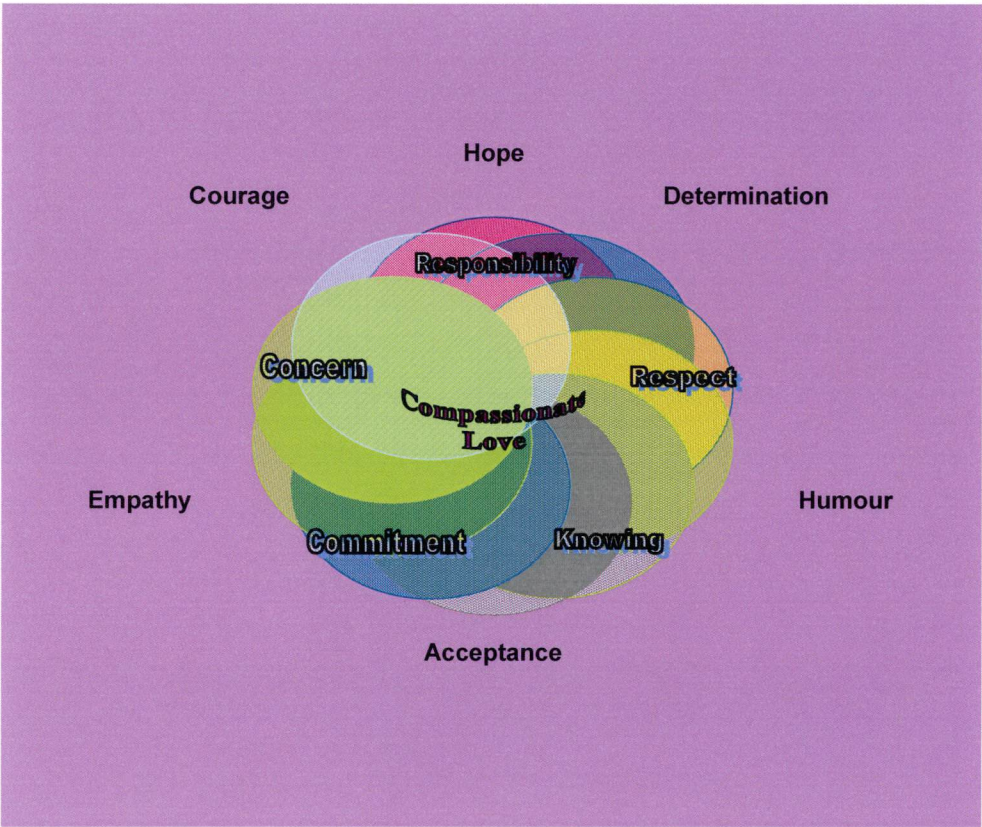
I maintain that compassionate love has two consequences. In the first instance, the care provided by the participants in this study to the person dying was extraordinary; in the second instance, for the person providing the care, the lived experience provided opportunities to learn in a very real way of their potential strengths and capacities. The remaining section of this chapter highlights the skills and competencies that people developed throughout their experience of attending to the death and final arrangements emanating from the gift of compassionate love.

People's Strengths

The qualities of people operating at end of life and beyond have been eclipsed by the risks and potential problem behaviours caused by bereavement. An oversight of these strengths, resources and capacities is understandable in light of people in the site of their home wanting to keep the scene of death a very private affair, as well as the tendency of healthcare workers to detach in the days following a death. A closer examination of the five practices of compassionate love uncovers a rich array of people's strengths, capacities and resources. The following model (Figure 6) places value on the qualities of care given expression through compassionate love at end of life. The qualities identified in this study include: courage; hope; determination; humour; acceptance and empathy.

This model does not intend to minimise the risks and negative aspects but seeks to restore some balance to the argument and move beyond the prevailing deficit model. A review of each of these qualities follows, commencing with courage.

Figure 6: The Lived Experience of Compassionate Love at End of Life.



Courage

Courage often existed in the same context as fear or dread. People had to frequently move beyond their familiar frames of reference and respond to the unknown. Being courageous was not a feeling or emotion that people experienced. Courage was an attitude which enabled people to do what they believed needed to be done. Staying with their significant other person, companioning them throughout end of life when visible and audible signs of death were evident, and bearing witness to the perceived suffering of someone as they pleaded for their life to end, were demonstrated acts of courage. Having

the courage to trust their own ability to make sound decisions was demonstrated by some participants who opted to participate in ways alternative to mainstream society, such as keeping their deceased person at home for as long as was considered necessary, challenging authority by undertaking tasks appropriated by professionals, and giving oneself permission to leave or avoid public gatherings.

Hope

Many participants had a strong awareness of the importance of hope. Hope was not about expecting miracles to occur, it was about having faith that their current situation would change for the better. When change and uncertainty played such a major role in people's lives, the use of hope inspired people to seek new directions. People's hope often shifted throughout their journey, depending upon what they experienced. This was clearly evident when participants realised that the suffering of their close other could only cease through death, and so their hope moved onto the event of death transpiring. Some people relied on their faith to provide them with inspiration and comfort. Religion offered people a belief system when meanings of life and death were being questioned, and was significant in providing a frame of reference for planning final arrangements, particularly with regards to the funeral service.

Determination

In this study, people learned about the power of determination. Achieving a death at home demanded a concerted effort and a willingness to adjust to a changing lifestyle. Determination sometimes assisted people when others criticised their efforts or undermined their ability to do the best for the person who was dying. Even when feeling exhausted and numbed by the effects of grief, participants still managed to make decisions and apply their strengths to action. This capacity was, in part, due to people's determination. Being determined to manage the negative effects of grief, some people engaged in physical activities, such as cleaning, gardening, running, and walking. By engaging in manual tasks, some people found it a useful way to direct their energies and divert their attention away from being consumed by their grief.

Humour

Many participants employed humour to help them manage times of adversity. Sharing their sense of humour with others was a pro-social behaviour which often helped to lighten situations. Remembering amusing moments, or making light of some incident prevented people from being overwhelmed by their sadness or despair.

Acceptance

Acceptance was another strength which emerged throughout the five practices of compassionate love. Acceptance was not synonymous with being helpless or powerless. Acceptance was about making a conscious decision to be open to what was happening, often resulting in a sense of relief. People's acceptance can be demonstrated in their experiences of acknowledging the reality that death would transpire in the foreseeable future. Embracing this knowledge enabled some people to fulfil their goals or commence final arrangements. Allowing the pain of grief was also an acceptance that people had experienced a profound and life-changing loss in their lives. Accepting help was a strength demonstrated by participants. In this study, the donation of food, receiving expressions of sympathy from members of the church and consenting to community services were important social supports. Seeking help was a strength demonstrated by participants. Visiting the doctor for advice about physical and psychological symptoms in early bereavement was a coping strategy that participants employed as an attempt to alleviate their distress. Attending classes and mutual support groups in early bereavement was undertaken by some participants. People's networks of close friends and family members were also instrumental in the coping of the death and final arrangements. Participants found immense comfort in being with others on whom they could rely on for unconditional support. Participants recognised how their connections with close others contributed to their wellbeing and purposely sought their company to alleviate their grief.

Empathy

A further strength to emerge from the five practices of compassionate love was empathy. Empathy was demonstrated in the capacity of participants to perceive how another person felt. People did not have to rely solely on the person to explain how they were feeling, as it was often people's skills in observing non-verbal cues which enabled them to intuit what the other person was experiencing. This was evident in people's experiences of seeking pain relief for the person dying or through staying with their significant other person as death approached. Responding to a person's distress required participants to be in the presence of suffering. Staying with the person often caused participants anguish but it also provided them with greater insight about the plight of the person dying and a deeper understanding of the lived experience. People's empathy extended beyond the person who was dying as shown in the support given to other people. This was evident when people responded to the grief of others when the news of the death was received or through the understanding of other people in the close network not being able to witness the dying process. Empathy was also evident in people recognising the pain caused by bereavement and enabled a shared understanding or a common bond from an experience caused by profound personal loss. From living the experience of attending to the death and final arrangements, participants explained how they gained greater insight to the journey and empathised for others who chose to follow a similar pathway.

This model has relevance to social work intervention because it is possible that people's strengths may never be recognised when they are sequestered by the chaos generated by grief. The model proposed in this thesis consists of five practices and six strengths. The metaphor of a kaleidoscope is useful to describe how this theory operates, by comparing each practice and strength to the individual shards in a kaleidoscope. When the individual shards lie fragmented and detached from one another, the overall image appears chaotic and random. It is only when the shards are rearranged to join together and viewed in a certain light that a new image appears, eventually coalescing to create a unified whole. Likewise, a new image is discovered from the sum of the smaller parts when the five practices of compassionate love connect with the different strengths. Rearranging the different practices and integrating new and emerging strengths enables

this experience at end of life to take on new meanings, demonstrating the dynamic and evolving nature of this model.

The next section of this chapter considers the implications of the study and its relevance to social work practice. In light of the limitations of this study, this section of this thesis makes several recommendations for future social work research. The small size of this research makes it suitable as a theory generative study, but makes no claim to generalisability. As this study has indicated, the experiences of twenty-eight people is not intended to be representative of every person who has attended the death and final arrangements of a significant other person who died at home from a life limiting illness.

Implications of the Study and Recommendations for Social Work Practice and Research

The implications for social work practice derived from the findings of this study relate to several key issues pertaining to social work intervention. The first point I wish to make concerns my stance against medicine's preoccupation with the risks of grief and its consequential scientific management.

The call by clinicians to include a new classification complicated grief into the *Diagnostic Statistical Manual of Mental Disorders IV* serves to pathologise a normal process which is expressed in individual ways. My concern is that the power and knowledge invested in medicine will promote grief and bereavement as a psychiatric disorder when it operates outside medicine's parameters of what is to be 'normal'. This 'welcome development' may work towards hindering the open discussion of people's experiences of attending to a death and final arrangements in the private space of the home, particularly when it has been identified in this thesis that the environment of home offers people freedom of expression. One example may include people being reticent to share their paranormal experiences for fear of being judged, but this research has identified, along with a growing body of other researchers, that paranormal experiences are more common than previously realised. Furthermore, this thesis debunks the

persistent myth that grief has a timespan. The legacy of loss experienced through grief may never disappear from people's lives.

The implications of these findings for social work practice are two-fold. First, the social work practitioner providing bereavement support needs to have a wide knowledge of the different theories explaining grief and bereavement. The traditional theories of grief and bereavement have originated from the discipline of medicine which continues to focus on problematic behaviours and risks of morbidity. Alternative ways of understanding grief and bereavement, such as Remembering Practices and Continuing Bonds, support the appeal from a growing body of researchers for a more creative and contemporary approach to understanding end of life issues (Bradey 1990; Doka 2001; Goldsworthy 2005; Kellehear 2005). Second, I maintain that social work educators must embrace this alternative body of knowledge to provide a more balanced perspective so that novice social work practitioners entering the field will have what Goldsworthy (2005, p. 167) refers to as a 'theoretically expansive approach' which is 'committed to diversity of experience and clients' strengths'.

My second point addressing implications for social work practice concerns the impact of people's interventions. This thesis has highlighted how people who provide interventions throughout this journey will be instrumental in shaping people's experiences. I maintain that it is important not to disrupt the flow of compassionate love by imposing personal values; making assumptions about people's capacities or seizing control because of the consequences of these actions can cause harm to the 'joint journey'. This requires the practitioner to consider how support is provided, and I believe an ethics of care approach which engages with moral and political responsibilities would be an effective means to facilitate the gift of compassionate love. At the heart of the ethics of care approach is a respect for the interdependence of people and their responsibilities to one another. It is important to acknowledge and respect the complex and diverse nature of people's relationships. This thesis has shown how some people who care for a person who is dying can demonstrate compassionate love yet not hold their significant other person in high regard. It is conceivable, therefore, that some people will return to a person from whom there has been a history of separation or estrangement, possibly due to domestic violence, particularly when an expartner with a life limiting illness may be the other

parent of children involved in the relationship. Furthermore, it is conceivable that some people who leave their own home to care for a person dying may be required to adjust to an environment which has few, if any, familiar social supports. The difficulty of predicting when death will occur means that those who travel from interstate or take leave from employment, study or family obligations, cannot know for how long they will be away from their own home, their own social networks and their other associated responsibilities. Since social work operates at the interface between people and their environments, the context in which people support a significant other person to die at home must be given due consideration.

Applying an ethics of care approach also requires the social worker to act competently and consider the response of the person receiving support. This means that the client remains at the centre of care and the social worker remains responsive to their needs. I maintain that effective social work support is embodied in an approach which values people's capacities, strengths and resources. Working with a strengths perspective aims to facilitate the empowerment of people for the purpose of achieving their goals, to celebrate their achievements and to identify the wisdom and insight which comes from lived experience. This approach does not intend to minimise or ignore signs of distress or potential problems. Rather than focus solely on the problem, it seeks to celebrate what is successful, identifying people's own resources, strengths and capacities to make a difference. Appropriate support from the social worker would involve a dialogic relationship with the client, asking what would be helpful, rather than making expert assumptions about what is needed. Timely support is also crucial, because people need to be aware of their options to make planning a real possibility.

In this thesis, I have shown that in contemporary western society, death at home remains on the fringes of most people's experiences, yet there is growing pressure from the Australian government to relocate death in the community. Hospitals have a central role to play in the provision of support for people at end of life. Hospital admissions for diagnosis, pain and symptom management, respite, or the terminal phase are opportunities for the social worker to make contact with patients and their significant others. In the discharge to home, hospitals must offer an integrated service delivery for the purpose of achieving continuity of care, not just throughout the dying trajectory but at

the time of death and throughout final arrangements. Already highlighted in the literature review and reasserted in this context is the claim that care provided by health care professionals at the time of death and in early bereavement should be regarded as a duty of care rather than an auxiliary act. Access to social work support can be enhanced by improved referral procedures, which includes the social worker promoting social work support at the time of death and throughout final arrangements.

This study has identified several areas for future directions for social work research. My first recommendation arises from my concern for the lack of research addressing hospital discharge processes specifically for people who have received the diagnosis of a life limiting illness. This area is worthy of enquiry because outcomes of people's care will be influenced by the support, education and communication conveyed by healthcare workers throughout a person's dying trajectory, particularly in the early phase when people have time to consider making final arrangements.

This thesis is missing the voices of people in indigenous communities and those from culturally and linguistically diverse backgrounds. It is plausible that carers from these groups may experience additional challenges such as language barriers, heightened feelings of separation from social support networks and a lack of understanding by others of their specific cultural issues. The voices of people who are in same- sex relationships who are discriminated against legally and socially in Australia are also absent. I believe that these voices would provide yet another dimension to the body of knowledge surrounding people's experiences of attending to the death and final arrangements of a significant other person who died at home from a life limiting illness and future recruitment strategies would need to consider the inclusion of these people in the community. I also suggest that the findings of this study offer a springboard for research into the experiences of people who have decided to undertake all final arrangements themselves. The experiences of the two parents in this study indicate that the reclamation of control and the honouring of the deceased person are powerful incentives to assume this responsibility, showing how therapeutic and financial rewards can be achieved from choosing this particular pathway. If social work is to play a role in empowerment, problem-solving and social change, this option of care warrants further investigation.

The final point concerning future directions for doing research in matters relating to death and bereavement involves the issue of competency. I recommend that anyone who embarks upon a similar endeavour engages with an ethics of care approach along with critical reflective practice. This field of research is demanding and challenging, and the moral and political responsibilities attached to this endeavour are considerable, but the rewards are rich and the journey is transformative.

Concluding Comments to Stage 6

I bring this thesis to a close with a letter addressed to the participants who shared their insights and wisdom for the purpose of this study. This letter embodies my experience of undertaking this enquiry and the transformative quality of doing heuristic research.

Composing this letter was done in response to being ‘thoroughly familiar with all the data in its major constituents, qualities and themes and in the explication of the meanings and details of the experience as a whole’ (Moustakas 1990, p. 31). It is also intended as a means to ‘leave the field’ (Marshall & Rossman 2006, p. 91) and show my gratitude to the people who opened up their lives in the hope that their experience would bring greater understanding of death and final arrangements to the wider community.

Dear participants

I write this letter as an expression of my gratitude, to thank you all for the wisdom you shared so honestly, and with such generosity. Your courage is evident in your willingness to contribute to this study, by contacting me, telling your stories and rekindling memories, some of which I realised had never before been spoken.

Your stories, sometimes whispered through tears, have come from a place of deep knowing, offering insight to events seldom heard in public places. These stories have offered me a greater understanding of what it means to be with someone throughout their dying, to be present when death approaches and, finally, to be for the person, acting on their behalf when death demands so much amidst a maelstrom of grief. You have also demonstrated through your lived experiences that compassionate love was the source which guided and sustained your endeavours, prevailing above the many challenges confronting you. Exhaustion, distress, ambivalence, fear, criticism and doubt loomed large in your lives, but the strengths embodied in your practices of commitment, responsibility, knowing, respect and concern, enabled you to

continue contributing to the lives of others, throughout their dying and beyond their deaths. Your strengths of courage, determination, empathy, faith, humour and acceptance may offer hope to others who decide to tread a similar path.

Your experiences have taught me how important it is that people employed at end of life do not interrupt the flow of compassionate love by assuming greater knowledge, imposing their values or through seizing control. You have reaffirmed my belief in the power of listening and the importance in asking what would be helpful. From your wisdom and insights I have realised the tenuous balance that exists between notions of care and power in the human service professions and I intend to use this knowledge to promote my own social work practice and to share this finding with others providing support to people at end of life and throughout bereavement.

I wish you peace and farewell.

Marg Hughes

Appendix 1: Cover Letter

Dear

My name is Marg Hughes and I am a PhD candidate at the University of Tasmania. Some years ago, my mother died from a life-limiting disease. I helped look after her and I witnessed her die at home. This experience led me to pursue a career in Social Work and I am now employed on a casual basis at a Palliative Care service doing grief and bereavement work. It also led me to wonder about death and dying in our society and to decide to do research in this area.

I am interested to hear other people's stories about how they supported a significant person in their life to die at home; what it was like to share the final moment of life with that person in their preferred site of the home and to be involved in making final arrangements for the person who died.

People's stories of their lived experience are a powerful means of offering other people an insight into a world beyond their own. Everybody's story is authentic and meaningful. Stories sometimes achieve an increased awareness and a better understanding of how other people live.

Death and dying are topics often considered difficult to discuss. This research aims to raise awareness of the subject in the hope of promoting a healthy community. Research shows that many people living with a life-limiting illness prefer to die at home, yet for many reasons, the majority of people die in a hospital or hospice. I am interested in knowing more about end of life experiences from the perspectives of lovers, spouses, friends, parents, children and siblings who enabled a person to die at home and were involved in making final arrangements.

If you would like to learn more about this project, I can be contacted on 63 24 3657, which is my telephone number for my office at the University of Tasmania. If I am

unavailable and you feel comfortable to do so, you may leave your name and contact number and I will phone you back.

If you wish to remain anonymous, please feel welcome to use another name. Your contact with me will be treated respectfully and confidentially.

Thank you for reading this letter and best wishes.

Marg Hughes

Date

Appendix 2: Information Document

To die at home: narratives of death.

A study of how people such as lovers, spouses, friends, parents, children and siblings experience the death and the final arrangements of a significant person who died at home from a life-limiting illness.

Why is this research being done?

Some years ago, my mother died from a long illness caused by a life-limiting disease. I helped look after her and I shared her final moment at home. Though the experience was often distressing and I still experience a pervasive sense of loss, I acquired insights into death and dying which have changed my life irrevocably. I later trained as a Social Worker and now work in a Palliative Care service doing grief and bereavement work.

This study aims to acquire insight into the skills and resources of people who support a person to die at home, from the end of life until the completion of final arrangements. It is hoped that the research will inform health care workers about the lived experience of death and thus improve support for people who choose to die at home and the people who are involved in making decisions for the deceased person.

What is involved in the study?

I am seeking the voices of 20 people who have
Looked after someone at home throughout the course of a life-limiting illness;
Been in the home at the time when the person died;
Been involved in making decisions for final arrangements;
Have experienced the death no less than 10 months ago;
Are over 18 years of age;
Speak English;
Live in Tasmania

If you wish to be involved, I will be asking you to participate in one, possibly two interviews which will be approximately 1 – 2 hours in duration. Participation is entirely voluntary and you may withdraw at any time during or after the interview. With your permission, I will be audio-taping and transcribing the interview. I will provide you with a typed copy of the transcript and ask for your comments.

What are the possible risks of being involved in this study?

The three areas of potential risk which have been identified in this research are:- Confidentiality and Anonymity and Risk of Emotional Harm. I have noted below the precautions taken to mitigate these risks.

How will confidentiality be maintained?

Consent forms will be kept separate from the transcripts. All face-to-face interviews will be done by myself and I will transcribe all interviews.

All transcripts, audiotapes and discs will be kept in a locked filing cabinet and all raw data will be disposed of after 5 years, as required by the Ethics Committee of the University of Tasmania. All contact with me will be treated confidentially.

How will your anonymity be protected?

Every attempt will be made to protect your anonymity. No identifiable information will be sought, though it is understood that throughout telling your story, some identifiable information may emerge. You will receive a copy of your transcript. If there is any identifiable information contained within the transcripts, including any other information you wish to edit, I will delete it from the records. The final report will be written so that no person will be individually identified. A copy of the final report will be available for you to read.

What happens if you become upset throughout the interview?

If, at any time, throughout the interview you become upset, we can stop the interview and you can decide whether or not to continue. I am a Social Worker who regularly

works with people who express their grief and I believe that I have the skills to interview sensitively. I will offer you contact details of support services if you wish to be referred.

Who can you contact if you have any queries or concerns?

This study has been approved by the Ethics Committee of the University of Tasmania and should you have any concerns or queries in this regard, please contact Amanda McAully, Executive Officer of the Human Research Ethics Committee (Tasmania) Network, on 62 26 2763. You may also wish to contact the Chief Investigator of this research, Professor Robert Bland, on 63 24 3528.

I have included with this information sheet, a statement of informed consent. This form will need to be signed by you prior to participating in the research.

I will telephone you to determine whether or not you wish to be involved in the project. Please be assured that your contact with me will be treated respectfully and with the utmost confidentiality.

Thank you for taking the time to read this information.

Marg Hughes
PhD student
Social Work

Robert Bland
Professor
Social Work

Appendix 3: Examples of Interview Questions

Hello

I thought I'd include with this package some of the questions I'll be asking participants. The interview is semi-structured, which means the questions are only prompts and other questions might arise throughout the course of the interview. The interview is also interactive, so that if participants want to, they can ask me questions as well.

Can you tell me about your relationship with the person you cared for?

How did your [partner or child or parent etc] die?

How did you enable your [partner or child or parent etc] to die at home?

What was your experience of being with your (partner or child or parent, etc) when they died?

What happened from the moment that your (partner or child or parent, etc) died?

What meanings do you make from the time of death to the completion of final arrangements?

How has life been different for you since the death of your (partner or child or parent?)

I'll also be asking whether there is anything participants would like to add which I have not asked.

Thank you for reading this and best wishes

Appendix 4: Statement of Informed Consent

STATEMENT OF INFORMED CONSENT

Title of Project:

To die at home: narratives of death

A study of how lovers, spouses, friends, parents, children and siblings experience the death and the final arrangements of a significant person who died at home from a life limiting illness.

I have read and understood the 'Information Document' for this study.

The nature and the possible effects of the study have been explained to me.

I understand that the study involves the following procedures:

One, possibly two, 1-2 hour interviews

The audiotaping and transcribing of the interviews

A thematic analysis of the data

Dissemination of the final report to several assessors and possible publication.

I understand that if I become upset during the interview, I may stop at any time or withdraw at any time without prejudice. I also understand that my comments may be identified by people who know me. I understand that every precaution will be taken to avoid this.

I understand that all research data will be treated as confidential.

Any questions that I have asked have been answered to my satisfaction.

I agree that the research data gathered for the study may be published provided that I cannot be identified as a participant.

I agree to participate in this study and understand that I may withdraw at any time without prejudice.

Name of participant _____

Signature of participant _____

Date _____

I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that she/he understands the implications of participation.

Name of researcher _____

Signature of researcher _____

Date _____

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